Exploring how practising mindfulness affects people's experiences of living with a long-term condition

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Abstract

There is increasing evidence that mindfulness meditation-based interventions (MMBIs) benefit people with many long-term conditions (LTCs), particularly in terms of psychological wellbeing. Most evidence however relates to short-term outcomes, and limited information exists about how people integrate mindfulness into life over the longer-term, and how this affects their experience. This PhD aimed to address these limitations through the research question: *How does practising mindfulness affect people's experiences of living with a LTC?*

A qualitative approach was adopted, using grounded theory to explore the processes of change. Using two-stage interviews, diaries and focus groups, data were gathered from 34 participants and seven trainers of Breathworks' mindfulness course. Almost all study participants reported a diversity of physical and/or mental health problems, many with multi-morbidity. Fieldwork was supplemented by a subsequent Cochrane-informed overview of systematic reviews and a critical review of qualitative studies of MMBIs.

Participants' experiences were predominantly strongly positive, identifying significant changes in thinking and behaviour. They described in detail how mindfulness had become part of their lives, enabling them to be more effective and responsive in their self-care. Analysis identified a core process and metaphor of '*Starting where I am'* on an unwanted journey to an unfamiliar place. This highlighted how people become more aware and accepting of their condition and its impact, but able to see it in a wider context, and thus to take appropriate action. The process was represented in five interrelated themes: *Getting a new perspective; Feeling equipped to cope*; *Doing life differently*; *Seeing a change;* and *Finding it difficult.*

Through exploration of existing chronic illness literature, the study suggests that mindfulness is a powerful facilitator of transition, through which people come to terms with challenging life events. Transition is associated with improved, self-directed self-management, which is significant to both people with LTC and healthcare providers.

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Glossary

ACT: Acceptance and Commitment Therapy – a mindfulness-based psychological intervention which does not include meditation as a core element. Further described in 2.3.4.

DBT: Dialectical Behaviour Therapy – a mindfulness-based psychological intervention which does not include meditation as a core element. Further described in 2.3.4.

GT: Grounded Theory – the qualitative methodology used in this research. See 4.4.2.

LTC: Long-term condition – defined in 2.2.1.

MBI: Mindfulness-based intervention – one of a range of interventions which base their approach on mindfulness. To be distinguished from MMBI (see below).

MBCT: Mindfulness-Based Cognitive Therapy – an intervention developed from MBSR (see below), incorporating elements of cognitive behavioural therapy. Further described in 2.3.4.

MBSR: Mindfulness-Based Stress Reduction – the first widely-used, standardised secular mindfulness intervention, developed by Jon Kabat-Zinn. Further described in 2.3.4.

MMBI: Mindfulness meditation-based intervention – a sub-group of MBIs which give a central role to *meditation* in the teaching of mindfulness. Discussed in 3.3.1.

TAU: Treatment as usual – a control group in a study receiving what is considered to be standard care for their condition i.e. not the intervention being researched.

TBC: Triratna Buddhist Community – the Buddhist organisation with which Breathworks has close links. See 5.2.1 for further information.

Chapter 1
Introduction

This study identifies how practising mindfulness affected the experiences of a group of people with a range of long-term physical and mental health problems who had attended mindfulness training between six months and nine years previously. The study particularly highlights the longer-term experience of mindfulness, identifying how people integrated it into their lives, and how this had in many cases affected both their thinking and behaviour in relation to their illness and lives in general.

This chapter begins by identifying the context in which the study is set, and then outlines its specific aims and intended contribution to knowledge and practice. A brief overview of the thesis structure and content is then provided, outlining how the research question was explored and what was discovered. The final section contains a brief discussion of the writing style used in this thesis.

1.1   Study rationale and aims

The study is located at the point where two growing strands of interest converge: providing effective care and support to people living with long-term conditions (LTCs), and identifying and understanding the effects of mindfulness-based interventions.

There is an increasing awareness of the need to find new ways to support people living with LTCs, both to enable them to have a better quality of life and to manage the demands on health services resources which their conditions present. Self-care is increasingly being recognised as a key element within this process, both for the benefits it may bring to people's health and wellbeing and the potential cost savings it may offer.

In parallel with this strand is a growing interest in the ways that mindfulness interventions, which first came to prominence in the 1980s, can improve a wide range of outcomes for people experiencing various challenges, including long term illness. There is increasing evidence that mindfulness provides a means for people to cope better with these challenges and to see improvements, particularly in their psychological health. The structure of these interventions also makes them a potentially valuable approach to self-management, as their intention is to teach skills and attitudes which people are encouraged to take and integrate into their lives.

It is in this context that the research is set, exploring how practising mindfulness affected people's experience of living with a LTC, including both changes in attitudes and behaviour in relation to their illness, of which their self-care formed a significant dimension.

Reviewing the rapidly growing literature, it became apparent there was an absence of knowledge of the long-term of experiences of practising mindfulness, and of how people with LTC integrated mindfulness into their everyday lives. There was also a lack of understanding of the variation in people's experiences, for example in relation to their

condition or patterns of mindfulness practice. These areas needed to be better understood in order to clarify mindfulness's potential to benefit people living with LTCs. In the light of these considerations, the following research question was developed:

How does practising mindfulness affect people's experiences of living with a long-term condition?

A number of subsidiary questions were also identified:

- How do people understand and describe their experiences (positive and negative) of practising mindfulness in relation to living with a LTC?
- In what ways and for what reasons do people with LTCs integrate mindfulness into their lives?
- How do people with LTCs perceive that practising mindfulness affects the way they relate to and manage their condition?
- In what ways are people's experiences similar, and how do they differ?
- Does the variation seem to relate to any identifiable characteristics e.g. condition, amount (e.g. frequency, length) of mindfulness practice, personal circumstances?

The research was designed to address these key questions, and its different elements are outlined below. Recognising the extensive existing literature regarding the chronic illness experience, and its limited discussion within the mindfulness literature, a further goal of this PhD was to explore and embed its findings in this context. The intention was to identify how experiences of mindfulness practice informed, and were informed by, existing understandings of how people learn to live with a LTC. The PhD therefore sought to clarify the role that mindfulness may play in enabling people to live well with long-term health problems. It also aimed to identify the specific changes in thinking and behaviour which both contribute to and result from this. Through this process, it was hoped that the research would provide clearer information and insight into the benefits of practising mindfulness, and the circumstances in which those benefits are likely to be obtained.

1.2   Thesis overview

Following this introduction, it contains nine further chapters as follows:

Chapters 2 and 3 review the existing literature and provide a context and rationale for the research. **Chapter 2** offers an overview of definitions and key issues in relation to LTC, including current policy initiatives. It also explores the varying understandings of mindfulness within both Buddhism, where it originates, and western psychology, where the majority of current research is being undertaken. An overview of mindfulness interventions is also provided. **Chapter 3** reviews the empirical research into mindfulness meditation based interventions to establish what is known about their effectiveness and how they are experienced by participants. Two different approaches are used: an overview of existing systematic reviews based on the Cochrane overview process; and a review of the qualitative literature, including a meta-ethnography of participants' experiences. The chapter concludes by summarising key findings and gaps in the research, and identifying the research question for the study.

Chapters 4 and 5 discuss the theoretical underpinnings and methods used in the research. **Chapter 4** identifies the key philosophical perspectives which informed the research, namely critical realism and feminism. The reasons for selection of a qualitative approach and the choice of grounded theory as an appropriate methodology are then considered. Issues of ethics and quality and how these were addressed within the study are also discussed. **Chapter 5** provides an account of the methods to address the research question. It describes Breathworks, the mindfulness programme from which participants were recruited and gives details of the phased recruitment process used. Data collection methods of two-stage interviews, diaries and focus groups are then explored, followed by details of how ethical practice was ensured in relation to research participants. The process of data analysis is then outlined, providing an account of how the key themes and categories were identified.

Chapter 6, 7 and 8 present the findings from the research. **Chapter 6** provides demographic information about the research participants, and is followed by two chapters which contain the findings from the interviews and focus groups. **Chapter 7** contains the majority of this material and is based on data from the interviews and one focus group. In this, the core process of *'Starting where I am'* is identified, together with three key themes: *Getting a new perspective; Feeling equipped to cope;* and *Doing life differently.* The relationships between these themes and two further supporting themes, *Seeing a change* and *Finding it difficult* are discussed. **Chapter 8** refines and develops these themes with data from the final focus group.

Chapter 9 provides further contextual information through a consideration of reflexivity, in which I consider my own perspective and experience and how this affected and was affected by the research. In particular I consider the role of my existing familiarity with mindfulness, and of a number of significant health challenges I faced during the study.

Chapter 10 discusses the findings from the literature review and the qualitative research, identifying how they contribute to the existing research into mindfulness interventions. It then explores how the findings relate to existing literature regarding living with chronic illness, particularly the model of transition. The insights gained into mindfulness and transition are identified, in particular its impact on self-care. Conclusions from the study are drawn and its strengths and limitations discussed, together with recommendations for future research and practice.

1.3   Use of first person writing style

In some chapters of this thesis I have used the first person writing style. Although most academic research still adopts a third person style, this reflects positivist assumptions that the researcher has no impact on the research, and is inconsistent with the interpretivist philosophical basis of qualitative research, the methodology used in this study, which recognises the role of the researcher in shaping the research process and its outcomes (Sandelowski, 1986, Hyland, 2001, Ritchie and Lewis, 2003). Indeed, Webb argues that if the researcher has *"played a crucial role in shaping the data or ideas presented....not to use the first person is deceptive and biased."* (1992, p747).   Use of the first person helps to

clarify my role in the collection, analysis and interpretation of the data, and is therefore an aspect of demonstrating credibility and quality in the research (Sword, 1999).

A first person writing style also gives a more *"active and immediate tone"* (Rubin and Rubin, 2005, p252). Richardson argues that the lack of presence of the author makes much qualitative writing difficult and boring to read, and regrets that scientific writing does not value literary qualities such as aesthetics and taste (2003). Whilst first person writing is certainly no guarantee of these qualities, it may improve communicability, which may in turn enhance aspects of the research's quality, particularly those concerned with its resonance and usefulness, as discussed in 10.3.2 (Charmaz, 2006).

Based on these considerations and Webb's guidance (1992), I have used the first person where I consider this helps to clarify the role I have played in the research, and where I am expressing my opinion. In other sections, when *"referring to a generally accepted body of knowledge or thinking, and when reviewing a subject in the light of the available evidence"* (Webb, 1992, p748), I have retained the use of a third person style.

Chapter 2
Literature Review: Context

2.1 Introduction

This literature review is divided into two chapters. This chapter provides contextual information for the research. It begins with information regarding long-term conditions, and outlines relevant issues and policies. An overview of mindfulness follows, which considers its different understandings in Buddhism and Western psychology, the two main disciplines within which it has been explored. It concludes with an overview of mindfulness interventions, and locates the intervention on which this research is based, Breathworks, within this range. This is followed by chapter 3, which reviews the empirical research into mindfulness interventions, considering its range, quality and findings.

2.2 Long-term conditions: the context

This section begins by defining the key terms 'long-term condition' and 'self-care' used within this thesis, as there is considerable variation in their usage. It then outlines key issues around these topics, particularly within the UK setting.

2.2.1 Long-term condition

A long-term condition is defined by the Department of Health as *"one that cannot currently be cured but can be controlled with the use of medication and/or other therapies"* (Department of Health/Long Term Conditions, 2010, p4). The WHO, using the term "chronic conditions", identifies similar characteristics: "*they persist and they require some level of health care management across time",* and notes this timespan may be *"a period of years or decades"* (2002, p11)*.* Recognising the changing nature of disease, the WHO also emphasises the need to extend the traditional definition beyond non-communicable diseases to include persistent communicable diseases such as HIV/AIDS, physical disabilities, persistent pain and long-term mental health problems such as depression (WHO, 2002). Despite the differences between these conditions, the issues facing people living with them can be considered similar in many ways, and may have a similar impact on those around them, including the need for treatment and management support from healthcare services. In this thesis, the term 'long-term condition' (LTC) is used, and is taken to include the range of conditions identified by the WHO.

2.2.2 Self-care

The terms self-care and self-management are often used interchangeably and without clear definition; however Rijken et al (2008) identify some key areas of difference. *Self-management* concerns the active engagement of patients in their treatment and their collaboration with healthcare practitioners in the management of their condition. The focus is on the participatory relationship, and on active self-management behaviours

undertaken between consultations to minimise the impact of the patient's LTC on their lives (Lorig and Holman, 2003, Rijken et al., 2008).   In contrast, *self-care* concerns the activities of daily living taken to improve health or prevent illness, and in particular actions people take for themselves, based on their own experience (Department of Health, 2005, Rijken et al., 2008). It refers to people with and without health problems, and may or may not be seen to include partnerships with health professionals. In some definitions, self-care therefore encompasses self-management, but has broader meanings which are not focused on the engagement with health professionals.

As this PhD explored participants' experience in relation to a wide range of activities, the term 'self-care' is used, defined to include partnerships with health professionals. 'Self-management' is only used to refer to specific initiatives to encourage this aspect of self-care.

2.2.3   The challenges and impact of LTCs

The rapid increase in LTCs has been widely identified and is affecting all parts of the world (WHO, 2002, Nolte and McKee, 2008). Although rates are increasing faster in other regions, the proportion of the population living with at least one LTC is particularly high in Europe. This is accompanied by an ageing population in which rates of chronic illness are notably higher (Nolte and McKee, 2008, Department of Health, 2012a). In 2006, between 20-40% of the EU population aged 15 and over reported a long-standing health problem (Nolte and McKee, 2008). Additionally, increasing numbers of young and middle-aged people are developing LTCs as a result of a variety of factors, including obesity (Pomerleau et al., 2008).

Over 15 million people in England alone are estimated to be living with a LTC (NHS, 2009, Department of Health, 2012a), but as this figure is based on a more limited range of conditions than that listed above, this may be a significant underestimate. Although the number of people with one LTC is relatively stable, the Department of Health anticipates a rise in those with multiple LTCs or 'multi-morbidity' from 1.9 million to 2.9 million over the decade from 2008 (Department of Health, 2012a). This trend also seen in other countries (Nolte and McKee, 2008). The term 'multi-morbidity' is used throughout this study as it most accurately reflects the complexity and range of conditions described by research participants. This contrasts with the alternative term 'co-morbidity', which designates an 'index condition' and other associated or secondary conditions (van den Akker, 1996, Valderas et al., 2009).

The management of LTCs is often complex, requiring co-ordination between a range of services and professionals; this is a significantly greater challenge for people with multi-morbidity (Nolte and McKee, 2008). People with LTCs often have greater need to access services, and as a consequence expenditure per head is much higher. Average health and social care costs are estimated at £1000/year for an individual without a LTC, £3000/year for someone with one LTC, rising to over £7000/year for three or more conditions (Department of Health, 2012a). In 2002, the WHO warned that if not successfully managed, chronic conditions would *"become the most expensive problems faced by our health care systems"* (p26). This prediction seems to be being fulfilled, with treatment and

care of people with LTC estimated to account for 70% of health and social care expenditure in England (Department of Health/Long Term Conditions, 2010).

Living with a LTC also presents significant challenge for the individuals affected. Healthcare provision is generally structured around acute, time-limited episodes of care, and is therefore less likely to meet the needs of people with on-going health problems requiring integrated treatment and support over time (Nolte and McKee, 2008). Inadequate management of a condition is likely to increase the risk of further complications, including mental health problems such as anxiety and depression. Chronic pain, a feature of many LTCs, is often not fully controlled by conventional treatment and is frequently related to high rates of depression (Bair et al., 2003). Similarly, people with depression and a number of other mental health conditions are at higher risk of developing such conditions as heart disease and diabetes (Department of Health, 2012a). In the UK, recognition of the link between physical and mental health outcomes has led to increasing provision of 'talking therapies' through the Improving Access to Psychological Therapies (IAPT) programme, and this has shown some positive outcomes (Department of Health, 2012a).

Other areas of life, including employment, mobility and daily functioning, are also often significantly affected by LTCs, particularly for people with multi-morbidity (Department of Health, 2012a). These factors are likely to impact on quality of life and economic status and, as LTCs are more prevalent in lower socio-economic groups, the link between illness and poverty is thus further reinforced (WHO, 2002).

2.2.4   The role of self-care

For both patient-benefit and economic reasons, self-care has become a major priority in many countries (Rijken et al., 2008). There is increasing recognition that only limited improvements in health outcomes are possible without the involvement of patients in their own care, both in terms of treatment decisions and everyday health-promoting behaviour (Rijken et al., 2008, Department of Health/Long Term Conditions, 2010). This has led to the establishment of a number of self-management programmes, most of which focus on individual conditions. Rijken et al note that systematic reviews and meta-analyses of these programmes have generally shown positive results, but not on all outcome measures. They also observe that many may not adequately address the needs of those with multi-morbidity, low motivation or who are disadvantaged, for example, by education, income or language.

Within the UK, the NHS Outcomes Framework identifies *"enhancing quality of life for people with long-term conditions"* (Department of Health, 2012b, p5) as one of its five key domains, and specifically includes self-management support (Department of Health, 2005, 2009). This has been translated into initiatives such as the Expert Patient Programme (EPP), based on the US chronic disease self-management programme. This encourages people to develop skills and confidence to manage their LTC in consultation with service providers (Expert Patients Programme, 2010). Feedback from a questionnaire sent to EPP participants (n=1000) indicated that besides improving quality of life, over 50% of respondents made less unscheduled visits to GPs and secondary care, and 35% reported a reduction in their use of medication (Expert Patients Programme, 2010). Reflecting Rijken

et al's (2008) observations however, some of the findings regarding the EPP and its US counterpart have been questioned. The methodological quality of some of the evaluation is weak, and there are inconsistent findings regarding changes in healthcare use (Griffiths et al., 2007). Improvements in self-efficacy, energy and quality of life have however been identified (Kennedy et al., 2007a). Better outcomes from professionally-led self-management programmes suggest that more targeting, a focus on changing health beliefs and teaching specific disease-management skills may be essential components (Griffiths et al., 2007).

Although most people with LTC wish to be involved in decisions regarding their treatment and care, this is not currently always borne out in practice for a variety of reasons relating both to individuals and the institutions they engage with (Department of Health/Long Term Conditions, 2010). The need to increase engagement and participation is emphasised (Department of Health/Long Term Conditions, 2010, 2012a), and self-management programmes appear to have a significant role in this. There are however institutional challenges in moving towards a more equal partnership, not least in terms of changing the attitudes of many healthcare professionals, who may be uncomfortable with the altered power relationship (Paterson, 2001a, Rijken et al., 2008, Expert Patients Programme, 2010). As noted previously, patterns of service delivery frequently do not meet the needs of those with LTC. There is therefore also a need for changes in the organisation of these services, if the partnership with patients is to be responsive and meaningful (Kennedy et al., 2007b).

Alongside treatment and management strategies, there is also recognition of the need to address individuals' attitude to their condition, which may affect their ability to self-care effectively. Reflecting the pattern of care provision, patients may have a perception of repeating acute episodes of illness rather than viewing themselves as having a LTC, as observed by Horowitz et al (2004) in relation to patients with heart failure. Others may not have fully acknowledged the impact of their condition, and the need to make significant life changes as a result, or may believe that they have no ability to influence their health (Rijken et al., 2008, Expert Patients Programme, 2010). A Department of Health report emphasises:

> *"Supporting people to self-care should start by supporting them to understand and accept their condition. By acknowledging that they have a LTC, individuals can begin the journey of developing knowledge, skills and confidence that can help optimise their quality of life and even slow the progression of their underlying clinical condition." (Department of Health, 2012a, p16)*

There is therefore a need for approaches which can support people with LTC to manage their conditions effectively on a range of levels, and it is in this context that mindfulness has attracted the interest of many health professionals.

2.3   Mindfulness: the context

The most widely used definition of mindfulness is:

> *"…the awareness that emerges through paying attention, on purpose, in the present moment, and non-judgementally to the unfolding of experience moment by moment…" (Kabat-Zinn, 2003, p145)*

Brown and Ryan however note that mindfulness is a *"concept that is difficult to characterise accurately"* (2004, p242), and a review of the literature confirms this assertion. This reflects both the complexity of the concept and the different strands of thinking which influence its understanding. It is even unclear whether mindfulness is the <u>outcome</u> of a process, as Kabat-Zinn's definition suggests, or the <u>process</u> itself: *"a natural process of experiencing whatever arises"*, as Rapgay and Bystrisky propose (2009, p157). Depending upon the definition used, mindfulness can therefore be considered a quality to be developed, i.e. a *state* of mindfulness, or the method used to develop it, i.e. *practising* mindfulness.

The most significant level of complexity in constructing a definition of mindfulness relates however to the different ways it is understood within the two major theoretical frameworks in which it is located: Buddhism and Western psychology. In the next section, the Buddhist roots of mindfulness are first identified and discussed, followed by some perspectives from within Western psychology, where the majority of current mindfulness research has taken place. Each perspective draws on its own philosophical underpinnings in identifying the components, mechanisms and purpose of mindfulness, and reservations have been expressed from both sides about aspects of the other's approach. The section concludes by exploring some of these tensions, and how they have been addressed.

2.3.1   Mindfulness in Buddhism

The practices and ideas associated with mindfulness originate within the highly developed philosophy of Buddhism (Bishop, 2002, Kabat-Zinn, 2003, Hayes and Shenk, 2004). As it is beyond the scope of this thesis to explore this in depth, only key aspects will be discussed here. Buddhism has a sophisticated understanding of psychology and consciousness, and its potential. It aims to make people *"much more than merely healthy….to open doors to states of consciousness that are beyond the imagination of Western psychology."* (Pauling, 1990, p3). The goals of Buddhist practice relate to the development of these higher states, with the ultimate aim of enlightenment, i.e. understanding the true nature of reality, oneness with all beings, and the cessation of suffering (Pauling, 1990, Hanh, 1991).

Mindfulness is located within a particular understanding of the nature of suffering encapsulated in what are known as the Four Noble Truths (Sumehdo, 1992, Knierim, 1999, Rahula, 2013), which can be summarised as follows:

1. Suffering, dissatisfaction or *dukkha*, is an unavoidable part of life;
2. Much suffering results from the desire for life to be a certain way, and a belief that happiness will result from the presence (craving) or absence (aversion) of particular things. As it is not possible to achieve or sustain this ideal situation,

attachment to achieving it creates suffering;

3. Reflection on and experiencing how attachment creates suffering provides understanding and insight, which is the route to becoming free of suffering;

4. The way to reach this goal is to follow a set of precepts or ethical guidelines known as the Eightfold Path.

The precepts of the Eightfold Path provide an integrated framework which addresses all areas of life and facilitates individuals' development towards their full potential (Pauling, 1990, Hanh, 1991, Rapgay and Bystrisky, 2009). The goals of this process are identified as loving-kindness, compassion (a desire to relieve suffering), sympathetic joy, and equanimity (Gunaratana, 2011, Hofmann et al., 2011). The precepts are often grouped into three sections concerned with wisdom (including right view/understanding and right thought/emotion), ethical conduct (right speech, action and livelihood) and mental discipline (Pauling, 1990, Rahula, 2013, Allan, 2013). Mindfulness, together with effort and concentration, forms part of the latter group.

Mindfulness, or s*ati*, can also be translated as complete or perfect awareness (Pauling, 1990, Allan, 2013), and is concerned with developing the *"mental ability to see things as they are, with clear consciousness."* (Knierim, 1999). Mindfulness encompasses awareness of all aspects of inner experience: the body, feelings or sensations, mind or consciousness, and mental phenomena. The goal of mindfulness is to develop a profound level of awareness which enables individuals to *"observe and recognise the presence of every feeling and thought which arises"* (Hanh, 1991, p37); this enables them to gain insight into themselves and their behaviour and ultimately into the true nature of reality.

Mindfulness is a fundamentally non-judgemental state, in which all experience is observed with *"bare attention"* (Gunaratana, 2011, p134). Mindfulness is distinguished from thinking, the latter being a conceptual activity in which experience is labelled and categorised and thus a form of judgement. It is rather the observation of the process of thinking: the focus is not on the object of perception but the perception itself. This enables a detachment - but not a disengagement - from inner and outer experience, which Gunaratana describes as *"participatory observation"* (2011, p135)

Through such observation, mindfulness is seen to enable recognition of the Four Noble Truths: how suffering arises from perceptions of events rather than from the events themselves, and from the patterns of thinking and behaviour that arise in response to these perceptions. The intention of mindfulness practice is not to change the external circumstances which trigger these patterns, but to change one's own internal state (Chiesa, 2013). By developing non-judgemental awareness, mindfulness enables a reduction in the positive or negative responses to events (the habits of craving and aversion) and the development of equanimity (Grabovac et al., 2011). Through mindfulness, habitual unconscious processes can also be observed and interrupted, rather than remaining automatic reactions (Gunaratana, 2011). This results in greater insight and control over the choices made in everyday life (Pauling, 1990).

Mindfulness supports a further goal of Buddhism: an insight into the true nature of things. This concerns the understanding that all phenomena are impermanent, cannot provide lasting satisfaction (thus causing suffering), and ultimately do not exist as separate from

everything else (Gunaratana, 2011). From this perspective, 'the self' as a separate entity exists only in perception, and this perception of separateness is considered one of the fundamental causes of suffering (Hanh, 1991). The practice of mindfulness, in particular through meditation, provides a way *"to pierce the inner workings of reality itself"* - to observe and experience the true nature of phenomena as transient and interdependent - and so gain insight and release from suffering.

Even within Buddhism, however, there are differences in how mindfulness is understood and practised. These reflect different schools of thinking, with some giving its role more emphasis within the ethical framework of the Eightfold Path (Kabat-Zinn, 2003). Differences also exist as to how the relationship between mindfulness and acceptance is understood. Some see acceptance as intrinsic to mindfulness, arguing that it is not possible to fully observe any experience without accepting that it is taking place (Gunaratana, 2011). In contrast, other Buddhist writers distinguish the two, viewing acceptance as a form of conceptual judgement which interferes with cultivating an entirely open awareness of experience (Rapgay and Bystrisky, 2009). There are also a range of understandings of mindfulness meditation practice, which will now be explored.

2.3.1.1 Mindfulness and meditation

Within Buddhism, meditation is considered the primary means of developing mindfulness. There is therefore a strong emphasis on the value of regular meditation practice, which is seen as the only means to attain higher levels of consciousness, and essential to maintaining the qualities of mindfulness in everyday life (Hanh, 1991, Gunaratana, 2011). Meditation however takes highly diverse forms, with mindfulness meditation being part of this range. Although no formal classification of meditation practices exists, Walsh and Shapiro (2006) note that they vary in the following ways:

- *type of attention:* maintaining concentration on a specific object e.g. an image, sound, the breath or an open, fluid awareness of all aspects of experience;
- their relationship to cognitive processes: to observe, or to try to change them;
- *their goal:* to foster general mental development and wellbeing or develop specific qualities such as concentration, loving kindness or wisdom.

Mindfulness meditation is part of a group of practices known as *vipassana* or insight meditations, which have wisdom and insight into the nature of self and reality as their goal (Pauling, 1990, Rapgay and Bystrisky, 2009). This is in contrast to concentration techniques, which have a goal of peace and tranquillity and act to calm the mind, focus awareness and encourage positive emotion (Pauling, 1990). Vipassana practice may take a variety of forms, but in mindfulness meditation an open, non-judgemental awareness of all aspects of present moment experience is cultivated (Kostanski and Hassed, 2008).

There are however differing understandings of what constitutes mindfulness meditation. Some suggest it contains elements of both concentration and open awareness (Chiesa, 2013), with concentration being initially used to slow down thought and develop sustained attention; this then supports the more advanced open awareness practices which lead to insight. Others consider only the latter practices to be mindfulness meditation (Pauling, 1990, Hanh, 1991, Gunaratana, 2011). There is however broad agreement that the two are

complementary (Rapgay and Bystrisky, 2009). Reflecting the blurring between process and outcome noted in 2.3, Hanh (1991) identifies mindfulness as both a means and an end; it is practised in order to build up concentration, but is also the awareness and awakening that results from this practice.

The recognition of the value of mindfulness in changing people's perspective on their experience has prompted its exploration and development as a tool to relieve suffering in a variety of contexts, as is identified in 2.3.4. In particular however, the qualities and skills that mindfulness claims to foster has led to considerable interest and investigation within Western psychology, which will now be explored.

2.3.2 Mindfulness in Western psychology

As is clear from the preceding sections, the traditional formulations of mindfulness are complex and deeply embedded in a philosophical and ethical framework. As this framework arose in a pre-scientific era in an Eastern cultural context, this has presented considerable challenges in 'translating' mindfulness to a Western scientific context, both practically and theoretically. There has been considerable 'unhooking' of mindfulness from its Buddhist origins. Interventions have been developed which aim to make mindfulness accessible to a wider audience, particularly by removing the focus on meditation and by introducing more psychologically-informed concepts. Work has also been undertaken to define the concept of mindfulness, and to identify psychological mechanisms to account for its beneficial effects. Although progress has been made, many authors note that this work has not yet produced a consensus (Bishop et al., 2004, Brown et al., 2007, Chiesa, 2013). A brief overview of some of the key ideas in this field will now be given.

2.3.2.1   Psychological understandings of mindfulness

The first operational definition of mindfulness was provided by Bishop et al (2004), who proposed a model of mindfulness with two components, each associated with particular behaviours and psychological processes: i) self-regulation of attention towards the present moment and ii) an open, accepting attitude towards experience.

Self-regulation, defined as *"the ability to behave adaptively while distressed"* (Baer, 2009, p19), is identified as a key psychological process in maintaining health and wellbeing (Hayes and Feldman, 2004, Bishop et al., 2004, Shapiro et al., 2006). Bishop et al (2004) draw on Carver and Scheier's work on self-regulation, which highlights how a sense of discrepancy between desired goals and actual reality can contribute to depression, distress and poorer physical health situation, particularly if the goals cannot be met or redefined (Scheier and Carver, 2003, Rasmussen et al., 2006). The acceptance developed through mindfulness can thus help avoid discrepancy and consequent problems by increasing people's ability to adapt to their situation.

Acceptance and openness to experience also develops a greater capacity to tolerate distress or difficulty, including pain and illness. Baer (2007, 2009) identifies how avoidance of difficult or distressing experiences is a significant factor in many psychological disorders including addiction, self-harm and a variety of anxiety disorders. Development of the

ability to observe experience non-judgementally, and *"to introduce a 'space' between ….. perception and response"* (Bishop et al., 2004, p232), is therefore an important skill, and forms a core element of psychologically-based mindfulness interventions. Although the language differs, this understanding of the role of acceptance echoes that outlined in the Four Noble Truths, as summarised in 2.3.1.

A number of writers emphasise the importance of the present moment focus of mindfulness, which facilitates direct contact with <u>actual</u> experience rather than being drawn into thoughts about it, including memories or anticipation, which often create further stress (Bishop et al., 2004, Biegel et al., 2009). Greater awareness of experience provides understanding of previously unconscious patterns of behaviour and thought, increasing the sense of choice and control (Baer, 2003, Allen et al., 2006). It can also increase people's ability to notice early indications of illness, particularly negative thinking patterns associated with depression (Lau and McMain, 2005). Baer identifies that although greater awareness of sensations, thoughts and emotions is correlated with many psychological disorders, it seems to be beneficial in this context (2007, 2009). She suggests that the flexible, non-judgemental qualities of mindfulness create a positive self-focused attention, which is not focused on negative aspects of experience and brings an attitude of curiosity and acceptance to thoughts, feelings and sensations.

Various authors suggest that as mindfulness creates the ability to be aware of one's own mental processes, it can be considered a metacognitive skill (Teasdale, 1999, Teasdale et al., 2002, Bishop et al., 2004, Lau and McMain, 2005).   Developing metacognition is seen as central to the process of change which mindfulness facilitates, reducing identification with thoughts and emotions, and belief in their validity as an accurate reflection of reality. Experiencing that 'thoughts aren't facts' is seen as key to changing the processes which increase the risk of depression, in particular reducing rumination, a repetitive process of negative, self-critical thinking (Lau and McMain, 2005). Through mindfulness, negative thoughts are instead observed and accepted as *"patterns of the mind"* (Teasdale, 1999, p154) rather than truths about the self or experience. This shift in perspective has parallels with the Buddhist concept of 'not-self' touched on above (Grabovac et al., 2011), and is variously termed decentering (Lau and McMain, 2005), defusion (Hayes et al., 1999) and reperceiving (Shapiro et al., 2006). It is a key concept in both Mindfulness-Based Cognitive Therapy (MBCT) and Acceptance and Commitment Therapy (ACT), interventions described further in 2.3.4.

Lau and McMain (2005) note that mindfulness approaches, with their focus on awareness and acceptance, challenge the prevailing Western understanding of the change process, where interventions focus on encouraging an alteration in people's behaviour and experience.   There are however differing views regarding Bishop et al's (2004) identification of acceptance as a distinct component of mindfulness. Brown and Ryan (2004) argue that it is integral and therefore define mindfulness only in terms of attention and awareness. Others view acceptance as a valuable support to mindfulness practice (Grabovac et al., 2011), or an outcome of it, rather than an integral part (Chiesa, 2013).

In contrast, Shapiro et al propose a three component model of mindfulness (2000, 2006). In addition to attention and attitude, which are similar to Bishop et al's components, this

model includes a specific component of intention, a dimension they consider has been lost in much of the psychological literature (Shapiro et al., 2006).   Shapiro et al suggest that openness, acceptance and kindness need to be <u>intentionally</u> brought to mindfulness practice to avoid a *"cold, critical quality"* (2006, p376) to attention and judgemental attitudes towards experience.   They also note that intention may change over time towards wider aspirations beyond symptom relief and that this enables deeper and greater changes in health which may not be facilitated by simpler models of mindfulness (Shapiro and Schwartz, 2000, Shapiro et al., 2006).

2.3.2.2   Distinguishing mindfulness from its methods and outcomes

Mindfulness interventions include a range of elements, presenting challenges in establishing the specific role of mindfulness in the process of change (Dimidjian and Linehan, 2003, Brown et al., 2007).   There is also a lack of clear distinction between mindfulness, the methods used to cultivate it, and the outcomes of practising it (Bishop et al., 2004, Hayes and Shenk, 2004, Brown et al., 2007).   For example, there are different understandings of the relationship between compassion and mindfulness.   Bishop et al identify compassion as an outcome of mindfulness, and thus not intrinsic to it (2004), whilst Shapiro et al see the *"heart qualities"* (2006, p377) of mindfulness as essential to its effective practice.   Kabat-Zinn notes that the words 'heart' and 'mind' are not separately defined in Asian languages, and emphasises that mindfulness therefore needs to include *"an affectionate, compassionate quality"* (2003, p145), a perspective which relates more closely to Buddhist understandings explored above.   There is also an increasing recognition of the role of compassion in accounting for the clinical benefits of mindfulness (Kuyken et al., 2010, Keng et al., 2012) whilst, as highlighted in 2.3.4.1, compassion meditation-based interventions appear to produce many similar outcomes.   There is therefore significant overlap between mindfulness and compassion as both an outcome and a method.

Another difference relates to the role of meditation.   Due to the traditional association of mindfulness with meditation, the two have in some instances been equated.   Others however contend that mindfulness can be developed through a variety of techniques, and thus any intervention producing this state can be considered a mindfulness technique (Hayes and Shenk, 2004, Brown and Ryan, 2004, Bishop et al., 2004). It is on this basis that ACT and Dialectical Behaviour Therapy (DBT) have developed, which do not include meditation as a standard element (see 2.3.4).   This has been seen as important in increasing the accessibility of mindfulness to people who may not engage with a religiously-derived practice, or whose health may present a barrier to meditating.   Concerns have however been expressed about the degree of separation of mindfulness from its Buddhist context in this and other respects, as will now be discussed.

2.3.3 Concerns and future directions

Whilst recognising the benefits of secularising and operationalising mindfulness within a Western psychological framework, a number of writers observe that *"it is possible that something is also lost in the separation of mindfulness from its spiritual roots"* (Dimidjian and Linehan, 2003, p167).   There are concerns that subtle but essential elements of its original complexity may be overlooked or dismissed, leading to a lack of understanding of the full potential of mindfulness practice (Dimidjian and Linehan, 2003, Kabat-Zinn, 2003,

Shapiro et al., 2006, Cullen, 2011(Dimidjian and Linehan, 2003, Kabat-Zinn, 2003, Shapiro et al., 2006, Cullen, 2011) and thus limiting its benefits to *"mere stress reduction"* (Cullen, 2011). The need for an approach which takes account of *"the perspectives of both the scientists and the meditators"* (Kabat-Zinn, 2003, p147) is emphasised as essential to fully investigating and understanding mindfulness. Others critique psychological measures of mindfulness, noting how these ignore some of its key aspects and complex inter-relationships, which may lead to biased research based on an inaccurate and narrowed interpretation of the concept (Rapgay and Bystrisky, 2009, Chiesa, 2013).

In response, attempts have been made to develop models of mindfulness interventions more closely based on Buddhist psychological theory and which provide a fuller understanding of how and why they work (Rapgay and Bystrisky, 2009, Grabovac et al., 2011). Grabovac et al suggest that most psychological models of change focus on attention regulation and acceptance, which are actually more strongly associated with concentration practices, and fail to take account of the full potential of mindfulness to offer insight into the true nature of experience (2011). Their 'Buddhist psychological model' draws on many of the ideas outlined in 2.3.1. In particular, they emphasise the importance of insight into the "three characteristics": impermanence, suffering, and non-self. Mindfulness is defined as *"moment-by-moment observing of the three characteristics […] of the meditation object"* (Grabovac et al., 2011, p4) which enables experience to be observed in a more detached way and a greater equanimity to be developed. Rapgay and Bystrisky (2009) similarly note that mindfulness practice consists not only of developing "bare attention" of present moment experience, but also of using this awareness to gain insight into the workings of the mind with a view to decreasing unhelpful thoughts, feelings and behaviour and increasing helpful equivalents. They suggest that as the latter stage of the process is not clearly identified in psychological models, the higher goals of mindfulness practice identified in Buddhism are not acknowledged and are therefore unlikely to be sought or achieved.

In summary, there is general agreement among mindfulness researchers on probably only two points – that there is no consensus around the definition of mindfulness; and that this lack of clarity has created considerable confusion and negatively impacted on research into its characteristics and dimensions (Dimidjian and Linehan, 2003). A number of attempts have been made to integrate Buddhist and psychological thinking around this topic (Walsh and Shapiro, 2006, Grabovac et al., 2011), but a recent review (Chiesa, 2013) highlights that these challenges remain, and it will take time, effort and continued dialogue between Eastern meditation practitioners and Western researchers to resolve them.

2.3.4 Overview of mindfulness interventions

A range of mindfulness-based interventions (MBIs) have been developed, reflecting the diverse understandings of mindfulness discussed above. These vary from secular, psychologically-underpinned programmes to those explicitly retaining Buddhist values and practices. Figure 2.1 indicates the relative relationship of the interventions to these two perspectives. The most significant of these interventions will now be described, including Breathworks, the intervention studied in this research. Compassion meditations, which share many similar features, are also briefly considered.

Figure 2.1 Mindfulness interventions and their underpinnings

| Vipassana retreats | **Breathworks** | MBSR | MBCT | ACT / DBT |

| *Buddhist values and approaches retained* | | | | *Western psychologically-based approach* |

MBSR: Mindfulness-Based Stress Reduction   ACT: Acceptance & Commitment Therapy
MBCT: Mindfulness-Based Cognitive Therapy   DBT: Dialectical Behaviour Therapy
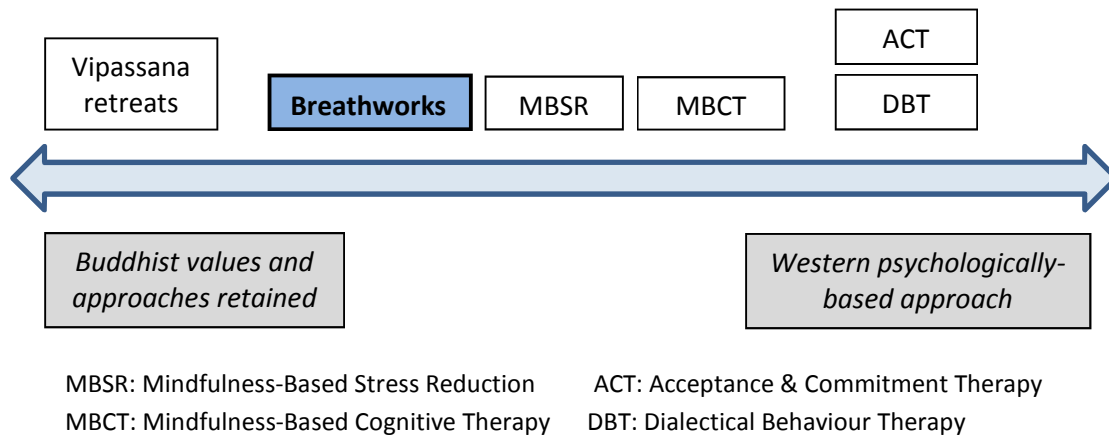
The first secular mindfulness course, *Mindfulness-Based Stress Reduction* (MBSR), was developed in the late 1970s in the USA by Kabat-Zinn. Initially designed to help teach "*the how of living with chronic pain*" (Kabat-Zinn, 1982, p34), it was extended to patients with anxiety and other LTCs, and generally taught to heterogeneous groups. The standard MBSR programme is a group-based eight week course of approximately two hours per week, plus a full day retreat. Participants are taught three 'formal' practices (a body scan, a breath-focused meditation and yoga postures) together with 'informal' practices which introduce mindfulness into everyday activities. A kindly awareness meditation may also be introduced near the end of the course (Kabat-Zinn, 1990). Participants are asked to commit to regular meditation and to practising mindfulness in everyday life, and are provided with written materials and CDs to support this (Kabat-Zinn, 1982). Sessions include teaching on stress and coping, and opportunities to discuss experiences of practising mindfulness. Trainers are expected to have their own regular mindfulness meditation practice so that they can teach from experience as well as knowledge.

MBSR has been introduced into a wide variety of settings where, in contrast to its origins, it has often been used with homogenous population groups. It is the intervention on which the majority of mindfulness research has been based. Although a structured programme exists, this has often been adapted to varying degrees by shortening the course and/or meditations or adding population-specific content (Toneatto and Nguyen, 2007). Other variations have included individual or internet-based teaching rather than group sessions.

More recently, and drawing significantly on Kabat-Zinn's work, *Mindfulness-Based Cognitive Therapy* (MBCT) was developed in the UK by Segal, Teasdale and Williams for people experiencing repeated depressive episodes (Teasdale, 1999, Segal et al., 2002). MBCT has a similar format and content to MBSR, with the same requirements of both students and teachers. It combines this with a number of elements from cognitive behavioural therapy (CBT), including learning to dis-identify from thoughts (Coelho et al., 2007) and the use of a short 'three minute breathing space' meditation. There is a growing body of research based on MBCT. Much of this is with the population for which it was

designed, but it is increasingly being used for a range of both physical and mental health conditions.

A third very similar programme is *Breathworks*, the intervention on which this study is based. Breathworks was developed in the UK at around the same time as MBCT (the early 2000s) by Burch (2008). It draws much of its inspiration and content from MBSR, but has evolved to contain some distinctive elements. In particular Breathworks has a more explicit focus on compassion, with kindly awareness meditation forming one of the core practices. Like MBSR, Breathworks originally focused on pain management but is now delivered to heterogeneous groups with a diversity of both physical and mental health problems (Breathworks, 2009a). Trainers are similarly expected to have their own regular mindfulness meditation practice. To date, very little research has been published on Breathworks. The programme is described in more detail in 5.2.1.

Breathworks is more closely associated with Buddhism than MBSR or MBCT due to its strong links to the Triratna Buddhist Community (TBC). It identifies itself however as a secular course, and has no expectations of religious belief or practice. In contrast, *Vipassana meditation retreats* have retained much more of the traditional Buddhist context. They are generally taught in the format of an intensive, mostly silent 10 day retreat where participants meditate for many hours each day. Although participants may not have a religious belief, the retreats often include teaching on aspects of Buddhism and its principles (Simpson et al., 2007). Research into vipassana meditation is currently very limited and generally of low quality (Chiesa, 2010).

At the other end of the spectrum of interventions are *Acceptance and Commitment Therapy* (ACT) and *Dialectical Behaviour Therapy* (DBT), both of which are much more closely based on Western psychological perspectives. ACT, developed by Hayes, uses a variety of approaches, including mindfulness and acceptance (Hayes et al., 2006), although mindfulness and meditation do not form such central components. The format, content and length of the intervention varies widely (Brown et al., 2007, Swain et al., 2013). ACT has been used with a wide range of mental and physical health problems.

DBT, developed by Linehan for people with borderline personality disorder, has generally been used with this and other related conditions (Linehan, 1993). Due to the high level of need in this population, DBT is often taught over a longer period of time and with greater support for participants (Baer, 2003). It draws particularly on Zen Buddhism and teaches six key mindfulness skills which are central to the intervention (Linehan, 1993). In recognition that some clients may be unable or unwilling to engage in meditation, this is not taught as a core mindfulness technique (Brown et al., 2007). Reflecting this, DBT trainers are expected to practise mindfulness in their own lives, but this may not take the form of meditation.

Within the range of MBIs, it can therefore be seen that there are significant variations in the way that mindfulness is taught to participants. One particular distinction concerns the role of meditation. It is a core element of MBSR, MBCT, Breathworks and vipassana interventions, but plays a much more limited role in ACT and DBT. In this PhD, only meditation-based interventions are explored in depth, and these are identified as M*M*BIs

(mindfulness *meditation*-based interventions), distinguishing them from the larger category of MBIs. This is further discussed in 3.1.1, in relation to the literature review.

2.3.4.1 Compassion meditation

As noted in 2.3.1.1, compassion and loving-kindness meditations differ from mindfulness meditation in their focus, and form another important strand of Buddhist practice (Hofmann et al., 2011). As they form an integral part of some MMBIs, particularly Breathworks, they will be briefly considered here.

The meditations generally involve focusing kindly attention and well-wishing towards a series of people, generally beginning with oneself and moving outwards to encompass a friend, a 'neutral person' and a 'difficult person', towards the whole of humanity. Interventions based on compassion meditation have been delivered in a non-religious form, although the format and content have varied considerably. Findings suggest that that compassion meditation may have a positive impact on a range of psychological outcomes, but the quality and quantity of evidence is too low for definite conclusions to be drawn (Hofmann et al., 2011). As noted in 2.3.2.2, there is growing interest in this area.

2.4   Chapter summary

This chapter has provided contextual information to the study. It has identified the significant and growing challenges of meeting the needs of people with LTCs, both for the individuals concerned and the services which provide care for them.   It then explored different understandings of mindfulness, considering both its origins in Buddhism and more recent interpretations within Western psychology. The complexity of the concept of mindfulness, and the difficulties in reaching consensus regarding its definition, have been highlighted. Finally, the range of MBIs developed to reflect these different perspectives have been outlined. Breathworks, the intervention used in this study, is located within this range as one of a group of MMBIs which are distinctive by their focus on meditation as a primary tool for teaching mindfulness. The next chapter reviews the empirical evidence for the effects of MMBIs on people with LTCs, through both an overview of systematic reviews and an in-depth exploration of the qualitative research.

Chapter 3
Literature Review: Empirical research

3.1 Introduction

The previous chapter explored the different conceptual understandings of mindfulness and the interventions these have given rise to. This chapter reviews and critically evaluates the published empirical research into mindfulness interventions, specifically mindfulness meditation-based interventions (MMBIs). It identifies what is known about their impact on people with LTCs using two approaches:

1) The variable quality of the growing body of quantitative research prompted a decision to conduct an overview of systematic reviews of evidence for MMBIs for people with LTCs;

2) A review of the qualitative literature was undertaken to identify its contribution to the knowledge and understanding of the impact of MMBIs on people's experience. This focused on an existing meta-ethnography, and also reviewed more recently published studies.

The chapter concludes by summarising current evidence for mindfulness, highlighting gaps in the research and identifying how the literature was used to inform the development of the research question for the thesis.

3.1.1 Use and identification of the existing literature

The use of a grounded theory methodology in this study (see 4.4.3) prompted a decision to delay a comprehensive review of the literature until after data collection and analysis were completed. This enabled participants' experiences to have a greater role in shaping the direction of the analysis, rather than existing understandings and knowledge of mindfulness. A preliminary critical mapping of the mindfulness literature was however carried out earlier in the process in early 2010, which highlighted the need to understand the longer-term experience of practising mindfulness and how this affected people's experiences of living with a LTC. These considerations informed the development of the research question, as outlined in 3.4.

Before the comprehensive review could be carried out, however, it was necessary to define which mindfulness interventions should be included in it, due to the diversity identified in 2.3.4. As there are currently only two published pieces of research into Breathworks (Cusens et al., 2010, Doran, 2014), it was not possible to limit the literature review to studies of this programme. It was however considered necessary to focus on interventions sharing a number of key characteristics, which were determined to be:

- inclusion of mindfulness meditation as a core element of the intervention;
- secular approach;
- group-based format of a similar length to Breathworks.

For the purposes of this thesis, interventions sharing these characteristics are defined as mindfulness *meditation*-based interventions (M*M*BIs) to distinguish them from the broader category of mindfulness-based interventions (MBIs). In addition to Breathworks, MBSR and MBCT were considered to be MMBIs. Other interventions were excluded for various reasons: ACT and DBT do not base their interventions on mindfulness meditation, whilst Vipassana retreats do not have a secular approach and the silent format significantly changes the group experience

3.2 Systematic review of reviews

The rapidly growing body of research into MMBIs shows strongly positive findings across a range of populations and settings. The methodological and reporting quality of this evidence is however very mixed, making it difficult to establish the reliability of its findings, both in terms of its relevance to particular conditions and the scope of its impact on the individuals who live with them. Additionally, the lack of active control groups in most trials has hindered the identification of the specific role of mindfulness within the process of change. A significant number of systematic and other reviews have been undertaken to clarify what the existing research into MMBIs offers reliable evidence for. These have had a range of purposes and scopes and have been carried out to varying standards. Rather than undertake a further review which duplicated this work, it was decided to conduct a systematic review of these existing reviews, informed by a process identified in the Cochrane handbook as an overview of reviews (Higgins and Green, 2011).

This relatively new form of systematic review is considered helpful when a number of systematic reviews already exist and the review question has a broad scope (CRD, 2009). It aims *"to compile evidence from multiple systematic reviews of interventions, into one accessible and useable document"* (Higgins and Green, 2011, p22.1.1). A number of potential reasons for undertaking such a review are identified, including *"to summarise evidence from more than one systematic review of the same intervention for different conditions, problems or populations"* (Higgins and Green, 2011, pTable 22.1.a). This reflects the intention identified in this instance. Using this approach, existing systematic reviews are assessed rather than the primary evidence on which they are based. Consideration is given to how rigorously the reviews have been carried out, and therefore how reliable their findings can be considered to be. Whilst Cochrane overviews generally focus on reviewing only Cochrane intervention reviews, the key elements of the process are more widely applicable and have been used here (Smith et al., 2011). As this work is based on the Cochrane process, the term 'overview' is used to describe this systematic review and to distinguish it from the systematic reviews which it considers. The overview process will now be described in detail, and the findings will then be considered.

3.2.1 Methods

3.2.1.1 Aim

The purpose of the overview was to identify, appraise and summarize the higher-quality evidence from systematic reviews that assess the effect of MMBIs on psychological and physical outcomes in people living with LTCs.

3.2.1.2 Search strategy

The search strategy and inclusion criteria were agreed by the review team, which consisted of myself (JL) and two of my supervisors (FA and MB). Searches were undertaken during November 2013 by one reviewer (JL).

Search terms were: "mindfulness", "mindfulness-based", "meditation" and "review". The following databases were searched: AMED, CINAHL, Cochrane Library, EMBASE, Medline, PsychInfo, Web of Science. As the majority of work on MMBIs has been published in the past decade, literature prior to 2004 was excluded as it would not take account of significant developments in the field. Full details of search strategies for each database are included in Appendix A.

Due to time constraints, and the diversity of journals publishing material related to mindfulness, no searches of 'grey literature' or hand-searching of journals was undertaken.

3.2.1.3 Inclusion and exclusion criteria:

Population
Included: over 18 years of age; having a LTC as defined in section 2.2.1, thus including both physical and mental health conditions.

Intervention
Included: MMBIs as defined in 3.1.1; delivered in a standardised structured format of weekly group sessions for between one and three months.

Excluded: MMBIs delivered on a one-to-one or online basis; other MBIs not considered to be MMBIs; other meditation interventions e.g. compassion meditation, Transcendental Meditation (TM) or yoga.

Outcomes
Included: all self-reported or clinically assessed outcome measures including physical, psychological and psychosocial; adverse effects.

Excluded: physiological parameters e.g. neurological or immune functioning.

Type of review
Included: systematic reviews, defined by: having an *a priori* question; identified inclusion and/or exclusion criteria; search strategy; and reporting of characteristics of included studies. Reviews including only RCTs, or which analysed the findings from RCTs separately; reviews where population and intervention either entirely meeting the above criteria, or a sub-group meeting these criteria identified and analysed separately.

Excluded: non-systematic reviews; reviews where relevant material was not separately analysed and could not be extracted.

Publication type
Included: English language; published in a peer-reviewed journal.

Excluded: dissertations; conference abstracts.

3.2.1.4 Review selection

Results of the searches were imported into Endnote. Following removal of duplicate entries, one reviewer (JL) screened the remaining items by title and then by abstract and, where necessary, by keywords to identify potentially relevant papers. Papers for which no abstract was available were excluded. Full copies of potentially relevant papers were then retrieved. A sample of ten reviews was independently reviewed by JL and either MB or FA (five each), using a checklist to determine inclusion or exclusion. There was 100% agreement on decisions regarding these reviews, and on this basis it was agreed that JL would review the remaining papers for inclusion, retaining any over which there was uncertainty. JL also searched the references of included papers for additional items. A flow diagram of study selection is shown in Figure 3.1.

3.2.1.5 Data extraction

A data extraction form was piloted with the first five reviews and then reviewed by the team, which led to clarification of the detail of information to be extracted and some minor amendments to the form. Data extraction of all papers was carried out by one reviewer (JL) and then checked by either MB or FA, with each reviewing half of the papers and highlighting any inaccuracies.

The reviews had significantly differing inclusion criteria with regard to mindfulness interventions. Some included only specific programmes e.g. MBSR, whilst others took in a range of MBIs. Even within this there was variation, with some allowing considerable modification of the standardised format, thus including studies which did not meet the inclusion criteria for this overview. As a result, data extraction in some instances required careful reviewing of the included studies, sometimes by retrieving the primary paper to check details of the intervention. In a few instances where only one study did not meet the inclusion criteria for the overview, the findings from the review and/or meta-analysis were deemed sufficiently relevant to be included as a whole.

3.2.1.6 Quality assessment

Quality assessment of the included reviews was carried out by two reviewers: JL (all) and either MB or FA (half each). The AMSTAR tool was used to assess the quality of included reviews, as this is specifically designed for use with systematic reviews and has been found to be reliable, valid and easy to use (Shea et al., 2007, Shea et al., 2009). Following discussion as a team, a system of scoring was agreed which allowed for recognition of partial meeting of criteria by use of half points. It was further agreed to assign reviews to three bands based on scores of up to 45%, 50-75% and more than 80% of criteria being fulfilled (due to one question being relevant only to meta-analyses, band scores varied on whether a systematic review or meta-analysis was being considered). When reviewers' scores were compared, they were found in most instances to fall within the same band, and this was deemed to be agreement. Where scores fell in different bands, often only by one point, disagreements were resolved by discussion and review of detailed AMSTAR scores to reach consensus.

Figure 3.1 Flow chart for inclusion of studies in systematic review

```
┌─────────────────────────────┐
│   3166 records identified   │
│ through database searches   │──────────────→ ┌──────────────────────────┐
│  and imported into Endnote  │                │ 1187 duplicates removed  │
└─────────────────────────────┘                └──────────────────────────┘
              │
              ▼
┌─────────────────────────────┐
│ 1979 records screened by    │
│ title                       │──────────────→ ┌──────────────────────────────┐
└─────────────────────────────┘                │  1596 records excluded:      │
              │                                 │ 1096 Not systematic reviews  │
              ▼                                 │ 279  Not using a MMBI        │
┌─────────────────────────────┐                │ 188  Not adults with LTC     │
│   383 records selected for  │                │ 33   No relevant outcomes    │
│      abstract screening      │               └──────────────────────────────┘
└─────────────────────────────┘
              │
              │                                 ┌──────────────────────────────┐
              │                                 │   279 records excluded:      │
              │                                 │ 219 Not systematic reviews   │
              │──────────────────────────────→ │ 29  Not using a MMBI         │
              │                                 │ 6   Not adults with LTC      │
              │                                 │ 1   No relevant outcomes     │
              │                                 │ 18  Not in English           │
              │                                 │ 3   No abstract              │
              ▼                                 │ 3   Duplicate publication    │
┌─────────────────────────────┐                └──────────────────────────────┘
│  104 records selected for   │
│    review of full paper     │
└─────────────────────────────┘
```

3166 records identified through database searches and imported into Endnote

1187 duplicates removed

1979 records screened by title

1596 records excluded:
1096 Not systematic reviews
279 Not using a MMBI
188 Not adults with LTC
33 No relevant outcomes

383 records selected for abstract screening

279 records excluded:
219 Not systematic reviews
29 Not using a MMBI
6 Not adults with LTC
1 No relevant outcomes
18 Not in English
3 No abstract
3 Duplicate publication

104 records selected for review of full paper

12 potentially relevant records identified through reference search and excluded

75 records excluded:
32 Not systematic reviews
8 Not using a MMBI
1 Not adults with LTC
1 No relevant outcomes
31 No extractable relevant data
1 Not in peer-reviewed journal
1 Could not be obtained

29 records met inclusion criteria for overview

2 records excluded:
1 Not systematic review
1 No extractable relevant data

27 records included and quality assessed

Whilst AMSTAR highlighted key areas of quality to be explored and provided a valuable focus for discussion, a number of limitations were also noted. Each criterion attracts equal weight in the scoring, which does not reflect their relative differences in importance to review quality, for example a declaration regarding conflict of interest attracts the same score as undertaking a comprehensive search or assessing the quality of included studies. Secondly, there were inevitable differences between reviewers in their interpretation of what was considered to be a partially, fully or not met criterion; these became apparent and were addressed during discussion of disagreement. Finally, as with other similar tools, failure to meet a criterion may have reflected poor reporting rather than necessarily being due to poor methodology; this is considered further below in the discussion of review quality.   For this reason, bands were considered to represent high, moderate and low degrees of confidence in the reviews' conclusions, and were designated by +++, ++ and + respectively.   No reviews were excluded on grounds of quality, as it was considered important to consider the whole range of available evidence.

3.2.2   Results

As the reviews considered a variety of populations and interventions, and many were in narrative form, it was not possible to carry out a meta-analysis.   The results of this overview are therefore presented as a narrative review and discussion.

As shown in Figure 3.1, searches identified 1979 potentially relevant articles. Following review of titles and abstracts, 104 of these articles were identified for further consideration. One could not be obtained (Igna, 2011); of the remaining 103, 29 were considered to meet the inclusion criteria. Two of these were subsequently excluded during data extraction on closer inspection, one having no extractable data (Hofmann et al., 2010), and the other not meeting the criteria for a systematic review (Langhorst et al., 2012).   An additional 12 potentially relevant articles were found through reference searches, but all were subsequently excluded through abstract or full paper screening.   A total of 27 systematic reviews were therefore included; however, two were largely duplicate publications (Fjorback et al., 2011, Fjorback and Walach, 2012), so their findings were combined in the overview.

3.2.2.1   Review characteristics

Characteristics of included reviews are shown in Figure 3.2, grouped by intervention and publication date order. The growing interest in mindfulness was evident in the increasing number of reviews being published, with only ten (38%) published up to and including 2010, and the remaining 16 (62%) since then. Country of publication was largely spread between Europe (10, 38%), USA (8, 31%) and UK (5, 19%), with individual reviews from Australia, Japan and Malaysia. Most (15, 58%) were solely qualitative systematic reviews, with a number noting that meta-analysis was not possible due to the heterogeneity and small number of trials (Baranowsky et al., 2009, Cramer et al., 2012a, Lawrence et al., 2013). Eleven (42%) performed some meta-analysis, although often on only part of the data for similar reasons (Bohlmeijer et al., 2010, Galante et al., 2013).

Figure 3.2 Characteristics of included reviews (by intervention)

Author, year and country	Type of review; whole or part included; no of included trials	Interven-tion for included studies	Population for included studies: health condition(s); mean % women; mean age	Findings and key points
Smith et al 2005 UK	SR Part (RCT only) 2 trials	MBSR including modified	Cancer, mostly breast; 98%	Methodological problems preclude firm conclusions on efficacy. Positive relationship between practice and outcome noted. MBSR warrants further research.
Morone & Greco 2007 USA	SR Part (MMBI only) 1 trial	MBSR	Chronic lower back pain, older adults; 74	MBIs suitable for older adults. One moderate quality study only: significant improvement in self-reported pain acceptance and physical function, but not pain.
Baranowsky et al 2009 Germany	SR Part (MMBI only) 2 trials	MBSR	Fibromyalgia	Significant improvement in depression compared to TAU at up to 2 months; however, physical and mental health outcomes no different in comparison to active control group: both showed improvement, which was maintained at 6-month follow-up. Findings considered promising, particularly in terms of lasting effect, but equivocal as MBSR-specific effect cannot be identified.
Ledesma & Kumano 2009 Japan	MA Part (RCT only) 4 trials	MBSR	Cancer, mostly breast, early stages; 79%; 50-57	Moderate effect size for mental health variables including anxiety, stress, sleep and quality of life. Small, non-significant effect size for physical health. Contrasts with previous meta-analysis, which was based only on self-report; when only self-report measures analysed here, effect size becomes significant. Drop-out rate sometimes associated with higher baseline rates of depression, anger and confusion.
Lunde et al 2009 Norway	MA Part (RCT & MMBI only) 1 trial	MBSR	Chronic pain in older adults: over 60	Small to medium effect size for depression, but non-significant effect on pain experience and physical function. Small effect on pain and physical function at follow-up. Use of a limited range of outcome measures prevented comprehensive evaluation of intervention's effectiveness.
Bohlmeijer et al 2010 Netherlands	SR & MA Whole 8 trials	MBSR, including modified	Various chronic physical diseases[1]; 88%; 45-55	Small but significant effect on depression, anxiety and distress. Some effect sizes lower than in other meta-analyses. Integrating MBSR and CBT (as in MBCT) may enhance effectiveness of MBIs.
Dissanayake & Bertouch 2010 Australia	SR Part (MMBI only) 2 trials	MBSR or similar	Rheumatoid arthritis	Positive changes in various measures of mental and emotional wellbeing but at different time points and insufficient data to draw strong conclusions. Some indication of greater improvement in joint tenderness and affect for those with recurrent depression compared to CBT, but less change in pain control – mindfulness may affect emotion regulation more than cognitive processes
Cramer et al 2012a Germany	SR Whole 3 trials	MBSR or similar	Chronic lower back pain; 55-76	Significant changes in pain acceptance, which is associated with improved pain and disability. Inconsistent findings for pain intensity and disability. Other positive changes e.g. sleep, emotional functioning based on insufficient data to drawn strong conclusions.

Author, year and country	Type of review; whole or part included; no of included trials	Interven-tion for included studies	Population for included studies: health condition(s); mean % women; mean age	Findings and key points
Cramer et al 2012b Germany	SR and MA Whole 3 trials	MBSR or similar	Breast cancer; 100%; 50-58	Small but significant effect found for depressive symptoms and moderate significant effect for anxiety. No significant effect for spirituality, although significant change in one study. Very little evidence for physical improvements. Other changes e.g. distress and coping, based on insufficient data to drawn strong conclusions.
Park & Hughes 2012 USA	SR Part (RCT & MMBI only) 2 trials	MBSR or similar	Lower back pain, older adults; 64%; 75	Adds to Morone, including second study with active control: no significant difference found between groups in reducing pain and disability, although more changes maintained at 4 months in MBI group. Insufficient evidence with rigorous design to conclude that MBIs effective in managing chronic pain.
Senders et al 2012 USA	SR Part (MMBI only) 1 trial	MBSR	MS	One high quality study only: significant improvement in quality of life, depression, fatigue and anxiety compared to TAU. Insufficient studies to provide strong evidence of benefit but no evidence of harm.
Lawrence et al 2013 UK	SR Part (RCT only) 1 trial	MBSR	Stroke/TIA; 52%; 57.4	One small mid-quality study only: small but significant decline in mental fatigue. Inconclusive findings re depression, anxiety, sensitivity to stress.
Lazaridou et al 2013 USA	SR Part (RCT & MMBI only) 1 trial	MBSR	Stroke rehabilitation	Include same study as Lawrence. Conclude that MBSR may be a promising treatment for mental fatigue after stroke.
Nenova et al 2013 USA	SR and MA Part (MMBI only) 1 trial	MBSR	Cancer with traumatic stress symptoms; 99%; 52	One study only: significant changes in some components of a post-traumatic stress measure compared to control. Approach noted to differ from other interventions by developing acceptance: may help with suppression and avoidance aspects of post-traumatic stress disorder (PTSD).
Zainal et al 2013 Malaysia	MA Part (RCT only) 2 trials	MBSR	Breast cancer 100%; 53.6	Moderate and significant effect size for changes in depression and anxiety compared to treatment as usual (TAU). Moderate but non-significant difference in perceived stress, but low initial levels.
Coelho et al 2007 UK	SR Part (RCT only) 2 trials	MBCT	Depression; 75%; 43-45	Significantly lower risk of depression relapse in patients with 3+ depressive episodes compared to TAU, but not in patients with 2 episodes.
Hollon & Ponniah 2010 USA	SR Part (MMBI only) 3 trials	MBCT	Major depression	MBCT efficacious in reducing the risk of depression relapse in patients with 3+ episodes who have been treated with medication. Differential pattern of effect different from CBT. Indications that MBCT more effective than antidepressants in reducing depressive symptoms and improving quality of life.
Chiesa & Serretti 2011a Italy	SR & MA Part (RCT only) 12 trials	MBCT	Various psychiatric disorders[2]	MBCT better than TAU for prevention of depression relapse for those with 3+ depressive episodes, but no significant difference for those with 2 episodes. Some evidence that MBCT plus discontinuing antidepressants no better for relapse prevention than continued antidepressant use, but may be better for the reduction of residual depressive symptoms in those with major depression. Other changes e.g. anxiety, QOL, sleep and findings re cost-effectiveness based on insufficient data to drawn strong conclusions.

Author, year and country	Type of review; whole or part included; no of included trials	Interven-tion for included studies	Population for included studies: health condition(s); mean % women; mean age	Findings and key points
Piet & Hougaard 2011 Denmark	SR and MA Whole 6 trials	MBCT	Major depressive disorder; 74%; 46	MBCT effective compared to TAU in reducing risk of depression relapse: highly significant result for 3+ depressive episodes in favour of MBCT and trend towards significance for 2+ episodes in favour of TAU. Indications that MBCT at least comparable to anti-depressant medication for relapse prevention and may be more effective for other symptoms but insufficient data to confirm.
Davis & Kurzban 2012 USA	SR Part (RCT & MMBI only) 1 trial	MBCT	Bipolar depression with history of suicidal ideation/behaviour; 18-65 in included study	Significantly lower anxiety and depression post-treatment compared to TAU, but no follow-up. MBCT a suitable treatment for this population. Low cost, potentially effective and easily adapted. Need for clarification of the particular role of the mindfulness and CBT elements of the intervention in its action.
Galante et al 2012 UK	SR and MA Whole 11 trials	MBCT	Psychiatric disorders, mostly depression[5]; 18-65 range in most studies	MBCT more effective at preventing depression relapse compared to TAU for those with 3+ episodes at 1 year. No significant difference for those with 2 episodes. Significant changes in depression at up to 1 year, and anxiety, but results less robust. Indication of reduced risk of relapse in unstable remitters only, similar to results from antidepressants. Other changes/ lack of changes in psychological and QOL measures based on insufficient evidence to draw strong conclusions.
Mars & Abbey 2010 UK	SR Part (clinical populations only) 10 trials	MBSR & MBCT, including modified	Mental and physical health conditions Most women (% not specified); 39-61 (where given)	Evidence from more than one high quality trial for reduction in depressive relapse, psychological distress and pain, and increased positive health. Positive changes in a range of other psychological and physical measures based on insufficient data to draw strong conclusions. MBIs may have the potential to impact a wide range of symptomatology in both mental and physical health conditions.
Chiesa & Serretti 2011b Italy	SR Part (RCT only) 6 trials	MBIs, mostly MBSR	Various chronic pain conditions[3]; majority women (% not specified)	Evidence from higher quality RCTs suggests MBIs could have non-specific effects for reduction of pain and depressive symptoms, but not specific effects. Some evidence of a specific effect on coping with pain, particularly in those with recurrent depression. Inconsistent evidence for impact on physical function. Insufficient evidence to determine magnitude of effects.
Fjorback et al 2011 AND Fjorback & Walach 2012 Denmark	SR Part (clinical populations only) 16 trials + 3 in second paper	MBSR & MBCT	Physical and psycho-logical conditions[4]; 77%; 51. Additional studies 86%; 48	Evidence from larger studies supports MBSR being superior to waiting list in improving mental health in both physical and mental illness. Changes sometimes related to increased mindfulness. Limited evidence for improvement of physical health. MBCT effective for relapse prevention in patients with 3+ episodes, with non-significant increased risk of relapse for 2 episodes. MBSR considered "well established and empirically supported", MBCT approaching "well established".
Piet et al 2012 Denmark	MA Part (RCT only) 9 trials	MBSR & MBCT	Cancer, mostly breast; 90%; 54	Small to moderate effect size in favour of MBIs for anxiety and depression, similar findings when only studies with ITT analysis included. Small, less robust effect size for these outcomes at follow-up, average 5.75 months. Small, less robust but significant change in mindfulness. MBIs equally or more effective than other approaches for cancer. Considered "an empirically supported psychological intervention" but lack of active controls prevent considering it specific.

Author, year and country	Type of review; whole or part included; no of included trials	Intervention for included studies	Population for included studies: health condition(s); mean % women; mean age	Findings and key points
Lakhan & Schofield 2013 USA	SR and MA Whole of MA, part of SR (RCT only) 12 trials	MBIs	Somatisation disorders including fibromyalgia, CFS and IBS; 94%	MBIs appeared efficacious in reducing pain, symptom severity, depression and anxiety, and improving quality of life. Symptom severity improved in all groups with overall small-moderate effect size, significantly greater change in standardised interventions. Results varied by diagnosis: greatest improvement in IBS (irritable bowel syndrome), least in fibromyalgia, others between.

[1] Fibromyalgia, cancer, lower back pain (LBP), rheumatoid arthritis (RA), chronic fatigue syndrome (CFS), heart disease

[2] Major depression (MD), bipolar disorder (BD), general anxiety disorder, panic disorder, social phobia

[3] Fibromyalgia, musculoskeletal pain, RA, LBP

[4] Multiple sclerosis (MS), cancer, chronic obstructive pulmonary disease (COPD), chronic pain, LBP, RA, fibromyalgia, social anxiety, distress, MD

[5] MD, BD, social phobia, depression in cancer

Some of the reviews were wholly relevant to the aim of this overview, whilst there were others where only some of the data were applicable. Reasons for partial relevance were varied. Some explored a wider range of populations or mindfulness interventions; others reviewed a variety of interventions for a particular condition or population. The latter illustrated the diversity of ways that mindfulness is categorised, it being variously termed a complementary therapy, a psychological therapy, a psychosocial intervention or a mind-body intervention. Conversely, other reviews using these terms did not include MMBIs, highlighting a lack of consistency. Five (19%) reviews could be wholly included, whilst relevant data had to be extracted from the other 21 (81%). As a result, relevant findings were frequently based on very limited numbers of trials; only five reviews (19%) included more than 10 trials, five (19%) between 5-10, and the remaining 16 (62%) less than five, including seven with only one relevant trial. The proportion of included data from reviews varied considerably from less than 25% to over 80%, and was less than 50% in only five reviews of MBIs. Reviews of a range of interventions had very few trials relating to MMBIs (maximum of three), but most could be included. Most included trials were also small scale, with less than a third having more than 100 participants (mean approximately 82.5).

Two reviews considered the effects of mindfulness interventions across all populations, whilst others focused on either individual conditions or groups of disorders. Eighteen (69%) reviewed a variety of physical health conditions, predominantly cancer (6, 23%) and chronic pain (5, 19%), with others including stroke, somatisation disorders including fibromyalgia (FMS), multiple sclerosis (MS), rheumatoid arthritis (RA) and. Mental health disorders formed the population for the other six (23%) reviews, with two focusing particularly on depression.

Most reviews explored a wide variety of outcome measures, in many instances probably all those which were investigated in the included trials. These were predominantly psychological, psychosocial and quality of life measures, with limited exploration of changes in physical symptoms or function. A few reviews considered only changes in specific symptoms pertinent to their aim. Almost all were self-report measures. A number of reviewers note the wide range of outcome measures used in the trials, and the challenges this posed for combining their findings; conversely Lunde et al (2009) observed that a limited range of outcome measures prevented full exploration of the potential of the intervention. Most outcomes were assessed immediately post-course, with little longer-term follow-up.

Trial population characteristics were often reported to a limited degree or not at all, which may reflect a lack of information in the primary data. Participants were predominantly female, with mean figures sometimes distorted by 100% female studies due to the conditions being studied (breast cancer and fibromyalgia). Reported age ranges were sometimes extremely wide, while mean age ranges varied from mid-40s to mid-70s, with the majority being in the 50s. A few reviews noted participants were predominantly white, western, with above average education.

Reviews also varied in the range of MMBIs included. Some specified either MBSR or MBCT; others included both. Yet others considered a wider range of MBIs; this was particularly true of the reviews of multiple interventions. Even within these specifications, reviews

varied in the degree of modification of the standardised interventions accepted, as discussed in the data extraction section above. It is notable however that even those reviews setting wide criteria often ultimately included only MBSR or MBCT, as trials using these interventions were the only ones meeting their criteria. This is unsurprising given the predominance of these two interventions in the research literature.

3.2.2.2 Exploring the quality of evidence in the reviews

Quality assessment of included trials was carried out in most reviews, with 16 (62%) using formal tools to do this. Some reviewers noted however that existing quality assessment tools did not adequately assess trials of interventions such as meditation, where blinding of participants is impossible (Baranowsky et al., 2009, Chiesa and Serretti, 2011a).

Concerns regarding methodological quality of trials were frequently raised. Inadequate and selective reporting of trial methods and findings created a risk of bias. This was further compounded by the use of a large number of outcome measures, which increased the likelihood of a chance finding of a positive outcome; this was a particular problem where no primary outcome had been specified. The lack of standardised interventions, small sample sizes leading to underpowered results, limited use of intention-to-treat analysis, and reliance on self-report measures were all highlighted. Frequent absence of information regarding adverse events and clinical significance of findings was also noted. Many emphasised how the lack of active controls in most trials prevented determining mindfulness-specific effects (Chiesa and Serretti, 2011a, Coelho et al., 2013). The complexity of MMBIs also presented challenges in identifying the role of different elements of the programme. The limited use of measures of mindfulness frequently precluded any direct association being made between changes in mindfulness and other outcomes. Finally, the predominance of immediate post-course outcomes largely prevented reviewers performing meta-analysis or drawing reliable conclusions regarding longer-term effects of MMBIs (Chiesa and Serretti, 2011b, Coelho et al., 2013).

Despite these limitations, a number of reviews identified at least some high quality studies. Mars and Abbey (2010) considered more than half of their included studies to be higher than average, Piet et al (2012) noted an average quality score of 2.9/4, whilst Bohlmeijer et al (2010) rated six of their eight studies as high (1) or medium (5) quality. Risk of publication bias was assessed by a number of reviews and largely not considered to be present, although the heterogeneity and small number of trials prevented definite conclusions being drawn (Chiesa and Serretti, 2011b, Lakhan and Schofield, 2013, Galante et al., 2013).

3.2.2.3 Exploring the quality of the reviews

As shown in Figure 3.3, reviews were of varying quality, with the large majority (14, 61%) falling in a band which indicated a moderate level of confidence could be placed on their findings. Five (19%) were considered high quality; these reviewed MMBIs for psychiatric conditions (Chiesa and Serretti, 2011b, Piet and Hougaard, 2011, Galante et al., 2013) or cancer populations (Cramer et al., 2012b, Piet et al., 2012). Six (23%) received a low score; as noted above, scoring in many instances reflected reporting quality rather than necessarily being an indication of methodological weaknesses.

Figure 3.3 Quality rating for included reviews

Author & year	Population and intervention	Quality rating*
Chiesa & Serretti 2011a	Psychiatric disorders, MBCT	+++
Cramer et al 2012b	Breast cancer, MBSR	+++
Galante et al 2013	Psychiatric disorders, MBCT	+++
Piet & Hougaard 2011	Major depressive disorder, MBCR	+++
Piet et al 2012	Cancer, MBSR & MBCT	+++
Baranowsky et al 2009	Fibromyalgia, MBSR	++
Bohlmeijer et al 2010	Chronic physical disease, MBSR	++
Chiesa & Serretti 2011b	Chronic pain, MBIs	++
Coelho et al 2007	Depression, MBCT	++
Cramer et al 2012a	Chronic pain, MBSR	++
Dissanayake & Bertouch 2010	Rheumatoid arthritis, MBSR	++
Lakhan & Schofield 2013	Somatisation disorders, MBIs	++
Lawrence et al 2013	Stroke, MBSR	++
Ledesma & Kumano 2009	Cancer, MBSR	++
Mars & Abbey 2010	Mental & physical health conditions, MBSR & MBCT	++
Morone & Greco 2007	Low back pain, MBSR	++
Park & Hughes 2012	Low back pain, MBSR	++
Senders et al 2012	Multiple sclerosis, MBSR	++
Smith et al 2005	Cancer, MBSR	++
Zainal et al 20013	Breast cancer, MBSR	++
Davis & Kurzban 2012	Severe mental illness, MBCT	+
Fjorback et al 2011 & 2012	Physical & psychological conditions, MBSR & MBCT	+
Hollon & Ponniah 2010	Depression, MBCT	+
Lazaridou et al 2013	Stroke, MBSR	+
Lunde et al 2009	Chronic pain, MBSR	+
Nenova et al 2013	Cancer with traumatic stress, MBSR	+
* Quality scores (AMSTAR): systematic reviews: + = 0-4.5; ++ = 5-7.5; +++ = 8-10 meta-analyses: + = 0-5; ++ = 5.5-8; +++ = 8.5-11		

The use of the AMSTAR tool highlighted a number of areas of weakness in many reviews. Details of an a priori design were often not provided beyond indicating the research question, although some referred to PRISMA and other existing schema. A significant number of reviews did not involve two people in the selection and extraction of data from relevant studies, or provided insufficient information to clarify this point, thus potentially reducing the objectivity and rigour of the process. Most restricted their searches to peer-reviewed, English language publications, and a few did not carry out comprehensive searches (e.g. using a limited number of databases or not searching other sources of data). These weaknesses increased the risk of relevant literature being overlooked, whilst very few reviews published details of excluded trials, making it impossible to determine the scope of their searches. All provided some characteristics of included trials, but details of populations and interventions were sometimes very limited. Although quality assessment of included trials was carried out in most instances, only a minority explored the risk of publication bias.

Although not explored within the AMSTAR framework, a number of other quality concerns were identified. Many reviews explored all outcome measures used in the included trials, with only some specifying primary outcomes for consideration, thus presenting a further

risk of bias towards positive findings. A significant number of reviews reported data without sufficient interpretation of their statistical significance, and there was even less exploration of the clinical significance of the findings. Very few reviews assessed the fidelity of the intervention to standardised MBSR or MBCT. This, combined with the variable definition of what constituted a MMBI, leaves considerable uncertainties regarding the quality and consistency of participants' experience.

Some reviews had inaccuracies or inconsistencies in their reporting of trial data. For example, Smith et al (2005) incorrectly reported negative findings from Speca et al's trial (2000) which actually identifies positive outcomes for MBSR, whilst Dissanayake and Bertouch (2010) reported there being no longer-term effect in a trial which in fact presents no follow-up data (Zautra et al., 2008). Other reviews either failed to report results fully (Mars and Abbey, 2010) or had inconsistencies between the results and discussion sections (Chiesa and Serretti, 2011a). In other instances, there were variations between reviews in their reporting of the same trials. This was particularly evident with regard to participant numbers, which sometimes differed significantly. In some cases this resulted from different calculations (e.g. including only completers or using intention-to-treat analysis), but many did not state the basis for their figures so this was impossible to ascertain. A second area of inconsistency concerned reporting of different sub-studies of the same trial data. Possibly reflecting a lack of clarity in the primary data, some reviews reported sub-studies separately, which may have distorted overall calculations and findings. As not all included trial details have been checked, it is possible there are other inaccuracies. This is a cause for concern when conclusions are based on such limited numbers.

3.2.2.4   Findings from the reviews

This section explores the key findings from the reviews, firstly by condition type and then identifying more general points across the data. Due to the inconsistent reporting of numbers of trials and participants described above, it was not possible to calculate definitive figures, but using data extracted from the reviews, I estimate that the findings of this overview are based on approximately 53 trials and 4373 participants.

Psychological conditions

The most consistent results were found in relation to psychological conditions, and in particular major depression. This is due to the fact that a number of robust trials have identified significant effects for MBCT in depression relapse prevention (Teasdale et al., 2000, Ma et al., 2004, Kuyken et al., 2008), this being the condition for which this intervention was designed (Segal et al., 2002). The most notable and reliable finding from these studies is that MBCT is significantly more effective than treatment as usual (TAU) for prevention of depression relapse in patients with three or more previous depressive episodes. This finding was noted in at least seven reviews, including a number of high quality (Chiesa and Serretti, 2011b, Piet and Hougaard, 2011, Galante et al., 2013). An accompanying non-significant result favouring TAU for patients with two episodes was also highlighted. Fjorback et al perhaps over-interpreted this result to question the potential risk of MBCT for this group (2011), whilst others reported it as 'no significant difference'.

The differential pattern of effects for MBCT was noted as distinctive compared to CBT (Hollon and Ponniah, 2010), and potential reasons for this were discussed in a number of reviews. These largely focused on the proposed different psychological mechanisms by which depression is triggered. In particular, internal low mood appears to be the main trigger for negative thoughts and depression in those with repeated episodes, compared to external events in those with fewer episodes. MBCT is hypothesised to be more effective in interrupting unhelpful internal connections than in changing the response to external triggers (Piet and Hougaard, 2011, Coelho et al., 2013). A number of reviews (Chiesa and Serretti, 2011b, Coelho et al., 2013) noted evidence to support this hypothesis in findings from one trial which identified significant changes in cognitive processes associated with depression (Williams et al., 2000). Another level of complexity in response was highlighted in findings indicating that MBCT and anti-depressants had similarly positive effects on relapse risk only in those with an unstable pattern of depression remission (Piet and Hougaard, 2011, Galante et al., 2013).

Other findings in relation to depressive disorders were consistent but less well supported, and indicated at the least a non-specific positive effect for MBCT. Compared to TAU, the intervention produced significant improvements in anxiety and depression in adults with bipolar disorder and a history of suicidal ideation or behaviour (Chiesa and Serretti, 2011b, Galante et al., 2013). MBCT plus gradual discontinuing of antidepressants was found to produce no significant difference in relapse rates compared to continued antidepressant use (Chiesa and Serretti, 2011b, Piet and Hougaard, 2011, Galante et al., 2013). There was however evidence that MBCT produced a significantly greater reduction in residual depressive symptoms when compared to continued antidepressant use/TAU (Hollon and Ponniah, 2010, Chiesa and Serretti, 2011a, Piet and Hougaard, 2011). Galante et al's high quality meta-analysis identified statistically and in some instances clinically significant changes in depression measures at up to a year, although only based on a small number of studies (2013).

Evidence relating to other psychiatric conditions was much more limited, and reviews did not find sufficient evidence to draw strong conclusions. A few noted changes in anxiety and other conditions compared to TAU, and in changes to other measures such as sleep or quality of life, but these were based on individual trials and were not consistent or conclusive (Chiesa and Serretti, 2011a, Fjorback et al., 2011, Galante et al., 2013).

Physical conditions

There was significantly more evidence relating to changes in psychological wellbeing in populations with predominantly physical conditions. Bohlmeijer et al's (2010) meta-analysis identified a small but significant effect size for measures of depression, anxiety and distress in populations with a variety of chronic physical conditions. A number of other reviews of specific conditions came to very similar conclusions. Chiesa and Serretti's (2011a) review identified non-specific effects for MMBIs on depressive symptoms in chronic pain populations, whilst Cramer et al's (2012b) higher quality meta-analysis found small and moderate effect sizes for depressive and anxiety symptoms respectively in cancer populations. Small but significant effect sizes for depression and anxiety in some

somatisation conditions, including fibromyalgia, were also identified (Baranowsky et al., 2009, Lakhan and Schofield, 2013).

Reflecting the considerable amount of research into MMBIs for cancer, a number of other reviews of both high and moderate quality also concentrated on this population, and meta-analysed data to reach similar conclusions regarding the impact of MMBIs on mental health measures (Ledesma and Kumano, 2009, Piet et al., 2012, Zainal et al., 2013). Piet et al (2012) reinforced these findings with small to moderate effect sizes for anxiety and depression from trials using intention-to-treat analysis. Individual trials also showed changes in distress, resilience, trauma, anxiety and emotional control, the latter two measures remaining significantly different at 24 months in one study (Cramer et al., 2012b). Other reviews found moderate or small but non-significant effect sizes for stress (Zainal et al., 2013) and spirituality (Cramer et al., 2012b) respectively. Findings were generally based on small numbers of trials predominantly using TAU controls, so can only be considered non-specific effects of MMBIs.

Evidence for other changes in cancer, and in relation to a range of other conditions and measures, were more limited largely due to the lack of trials rather than negative findings. Lakhan and Schofield (2013) identified small to moderate effect sizes for changes in symptom severity across a range of somatisation conditions, and changes in pain, quality of life and mental health measures in individual conditions. A differential effect was noted, with greatest improvement in irritable bowel syndrome (IBS) patients and least in fibromyalgia, with chronic fatigue and other conditions in between. There were indications of positive change in psychological and psychosocial measures in populations with heart disease (Mars and Abbey, 2010), rheumatoid arthritis (Dissanayake and Bertouch, 2010), MS (Senders et al., 2012) and in mental fatigue in stroke (Lawrence et al., 2013), but these were based on one or two studies. Mixed findings were noted in relation to changes in measures of quality of life (QOL) (Cramer et al., 2012b, Lakhan and Schofield, 2013). Lakhan and Schofield (2013) however questioned whether these could be attributed to the use of different outcome measures rather than any condition-dependent variation, with a condition-specific QOL measure showing significantly greater improvement than a general one. A wide ranging, moderate quality review of all Axis 1 and clinical conditions identified statistically significant change in at least one high quality trial in measures of depression recurrence, pain, positive health and distress (Mars and Abbey, 2010).

The most notable area of inconclusive findings was in relation to physical health measures, including pain, fatigue and function. A number of reviews found no change in such measures in the majority of included studies (Chiesa and Serretti, 2011a, Fjorback et al., 2011, Cramer et al., 2012a), whilst findings in relation to sleep were also inconsistent (Cramer et al., 2012a, Cramer et al., 2012b). Park and Hughes (2012) noted that promising results of a pilot trial for lower back pain were not repeated when an active control group was used, where no significant difference between the groups for pain and disability was observed. In contrast, small but significant changes in pain measures, and small to moderate changes in symptom severity were found for somatisation disorders, particularly IBS (Lakhan and Schofield, 2013). Positive changes in measures such as pain reduction and

fatigue were also noted in other individual studies, particularly in relation to TAU controls (Dissanayake and Bertouch, 2010, Mars and Abbey, 2010, Senders et al., 2012).

An interesting insight into the distinctive effects of MMBIs was offered by Ledesma and Kumano's moderate quality meta-analysis (2009). They calculated a small non-significant effect size (d=0.17, 95% CI -0.07-0.40) for physical health measures in cancer patients, but this figure achieved statistical significance (d=0.26, 95% CI 0.13-0.38, p<0.0001, two tailed) when only self-report rather than physiological measures were included. This pattern was further reinforced by changes noted in a number of reviews of different conditions in measures of pain acceptance and coping (Dissanayake and Bertouch, 2010, Cramer et al., 2012a, Cramer et al., 2012b). Additionally, Nenova et al (2013) identified improvements in trauma-related stress symptoms including reduced avoidance of experience in one trial with a breast cancer population. These findings suggest that participants' experience of their symptoms may sometimes be more significantly changed than apparent from clinical assessment, a point which is discussed further below.

Relationship to home practice and mindfulness levels

MMBIs generally place an emphasis on regular home practice, but the reviews highlighted an inconsistent relationship between practice and outcome measures (Mars and Abbey, 2010, Fjorback et al., 2011, Chiesa and Serretti, 2011b). This was based on limited numbers of trials, but reflects the findings in Vettese et al's non-included review (2009), which found only about half the trials showed a correlation between home practice and outcomes. Additionally, few trials used any measures of mindfulness, so there was limited data in the reviews regarding how changes in mindfulness related to other outcomes. Fjorback et al (2011) noted some correlation between mindfulness and mental health outcomes, whilst Piet et al (2012) performed the only meta-analysis of changes in mindfulness measures to identify a small but significant effect size, based on five studies.

Mindfulness-specific effects

The majority of results were based on TAU or waiting list controls, and findings for studies with active controls were much more inconsistent. Through examination of the reviews' included papers, 15 studies with some form of active control were identified (28% of the total), with controls including education or support groups, cognitive behavioural therapy (CBT), massage and antidepressant medication. Of these, nine (60%) identified no significant difference between the two groups, both often improving significantly. Two studies (13%) found significantly greater improvement in the MMBI group, and the remaining four (27%) portrayed a more complex but potentially illuminating picture of differential improvement between the two groups. Although these data were very limited, there were some indications that MMBIs had a greater effect and more lasting effect on mental health compared to massage, but less effect on pain (Plews-Ogan et al., 2005), and a greater effect on emotional regulation compared to CBT but less effect on pain control (Zautra et al., 2008). Findings in the latter trial, including those for pain coping, were significantly more positive for those with recurrent depression, reflecting the differential effect on relapse prevention discussed above.

Longer-term effects

As noted above, limited evidence was available regarding longer-term effects of MMBIs. Piet et al performed the only meta-analysis of follow-up results in four trials to identify positive but inconclusive results an average of six months after training (2012). Other reviews noted individual trials which support these results, showing equal or greater improvement compared to controls in the longer term (Cramer et al., 2012a, Cramer et al., 2012b, Park and Hughes, 2012, Piet et al., 2012, Galante et al., 2013). A few trials indicated that MMBIs may have a cumulative effect, with changes only being apparent at follow-up (Plews-Ogan et al., 2005, Pradhan et al., 2007, Gaylord et al., 2009). This pattern was also suggested by data relating to cost-effectiveness, which Piet and Hougaard (2011) observed to show a difference between MBCT and antidepressants only in the last three months of a 15 month trial.

Clinical considerations

Considering their use in practice, MMBIs were found to be acceptable and adhered to by all population groups (Fjorback et al., 2011, Chiesa and Serretti, 2011b, Piet et al., 2012, Davis and Kurzban, 2012), although Morone and Greco (2007) suggested modifications may be necessary for older participants. No serious adverse effects were identified, although this information was frequently missing from studies (Morone and Greco, 2007, Chiesa and Serretti, 2011b, Cramer et al., 2012a). There was also some preliminary evidence for MBCT being at least as cost-effective as antidepressants for depression relapse prevention and treatment (Chiesa and Serretti, 2011a, Piet and Hougaard, 2011, Galante et al., 2013). A number of reviews concluded that MMBIs offered a low cost, low-resource, potentially self-sustaining non-pharmacological approach which may form a valuable component of treatment in a number of conditions (Piet and Hougaard, 2011, Davis and Kurzban, 2012, Fjorback and Walach, 2012, Lakhan and Schofield, 2013, Lawrence et al., 2013).

3.2.3   Discussion

Whilst there were significant limitations in both the quantity and quality of evidence for MMBIs identified through this overview, some findings seem to be well supported. There was consistent evidence for depression relapse prevention compared to TAU for those with a pattern of recurrent depression, which is reflected in MBCT's recognition in the UK as an effective therapy for this condition (NICE, 2009b). There was also considerable evidence to indicate that MMBIs improved the mental and emotional wellbeing of people with a range of health conditions, reducing distress, anxiety and depression, at least in comparison to TAU.

The evidence for changes in physical symptoms was inconsistent, but improvements in measures of pain acceptance and coping suggested a changed relationship to those symptoms. This is consistent with the goals of the interventions (Chiesa and Serretti, 2011a). As Fjorback et al (2011) observed, MMBIs seemed to impact on people's inner rather than outer experience, and taught coping skills to handle their condition. An emphasis on acceptance was noted as a distinctive feature of MMBIs and a useful

complement to the predominant, change-focused model of many interventions (Piet et al., 2012). Acceptance and openness to experience were also highlighted as key skills and attitudes in facilitating improvements in post-traumatic stress disorder (PTSD) symptoms in cancer (Nenova et al., 2013), suggesting another means by which people may experience a changed relationship to their condition. It is possible that trauma may be an aspect of people's experience of other LTCs, and so this finding may be more widely generalisable.

The generic nature of MMBIs, combined with indications of benefit, acceptability and a lack of adverse events across a wide range of populations, suggests that they may have broad potential application, although some of these features were under-reported in both the reviews and primary data. There is a need for better understanding of the relationship between home mindfulness practice and outcomes, particularly given the significant demands it makes on people's time (Piet et al., 2012). Questions regarding the relative importance of different components of MMBIs also need further exploration, including the contribution of the mindfulness and CBT elements of MBCT (Davis and Kurzban, 2012) and, more fundamentally, the role of meditation and the impact of maintaining or disconnecting mindfulness from its spiritual and cultural roots (Mars and Abbey, 2010, Lazaridou et al., 2013).

Although a considerable amount of research into mindfulness has been undertaken, most was not been of sufficient quality to be included in the reviews considered in this overview. As noted above there were also significant limitations to the included data in terms of its heterogeneity, quality and quantity. These factors prevented definitive conclusions being drawn in many instances. Findings could generally not be explored by population or trial characteristics (Piet and Hougaard, 2011, Chiesa and Serretti, 2011b), and a number of reviews emphasised caution in generalising results to other populations. Lakhan and Schofield's (2013) findings highlighted the need to explore possible variation by condition, whilst indications that standardised, more comprehensive MMBIs demonstrated better outcomes (Cramer et al., 2012a, Lakhan and Schofield, 2013) require further investigation. Finally, lack of follow-up data precludes a clear understanding of the long-term effects of MMBIs, although there are indications that positive changes are maintained over time.

The low number of trials with active controls and the inconclusive nature of the data from these studies means there is currently a lack of evidence of specific effects for MMBIs (Fjorback et al., 2011, Park and Hughes, 2012). For these reasons, Piet et al categorise MMBIs as an *"empirically supported psychological intervention efficacious for […] anxiety and depression in cancer patients and survivors"* (2012, p1016) but note that it *"cannot be said to be efficacious and specific".* There is clearly a need for well-reported, high quality, larger scale trials with active controls which will address these shortcomings and clarify the particular ways in which MMBIs achieve their outcomes. A number of potential mechanisms have been proposed, as was discussed in 2.3.2.1, but the paucity of studies specifically designed to explore how these may operate prevents any firm conclusions from being drawn (Davis and Kurzban, 2012).

Despite these concerns, the findings across the reviews, regardless of quality, indicated a strongly consistent and positive pattern of change irrespective of condition or intervention. Evidence from the highest quality reviews confirms these findings in the two areas where

there is the greatest body of research: psychiatric conditions and cancer, particularly breast cancer. Findings were generally considered to be consistent with earlier systematic reviews and meta-analyses (Cramer et al., 2012b, Piet et al., 2012, Galante et al., 2013, Zainal et al., 2013), with smaller effect sizes in some instances possibly due to low baseline levels of symptoms, different inclusion criteria and the exclusion of uncontrolled trials (Bohlmeijer et al., 2010, Cramer et al., 2012b, Nenova et al., 2013, Zainal et al., 2013).

A final point of general concern was the large number of systematic reviews published in proportion to the amount of relevant research data. A mean of 4.9 trials and 416 participants per review were included, with only five reviews (19%) containing more than ten relevant trials. Even taking account of the fact that some reviews contained substantially more trials whose findings were excluded from this overview, many were based on very little data. Some also explored very similar questions, replicating previous findings to a considerable extent. The current overview included 26 reviews, but many others were excluded, at least some of which add further duplication. This *"plethora of reviews"* is noted by Smith et al as an increasing problem across the healthcare sector (2011, p1). It is therefore important that future potential reviewers take account of this existing body of work and consider carefully whether sufficient additional primary research has been published to make another systematic review worthwhile.

3.2.4   Strengths and limitations

This review is the first to draw together the findings from the considerable quantity of existing systematic reviews of MMBIs and to identify the areas where there is higher quality evidence for their effects and where this is still lacking. The methods and reporting of the overview were based on Cochrane guidance, helping ensure that a systematic and thorough process was used. A team of three reviewers were involved in designing and carrying out the review, with two reviewers being involved in most of the decisions regarding inclusion, data extraction and quality assessment. This brought greater rigour and objectivity to the process, as well as the combined experience and knowledge of the team regarding both the subject and the methodology (Smith et al., 2011).

Conversely, the fact that searches and initial screening was carried out by only one person is a limitation, and it is possible that potentially relevant papers were excluded as a result. To address this risk, an over-inclusive approach to selection was taken at this stage (Higgins and Green, 2011). A second limitation was the inclusion only of reviews published in peer-reviewed journals; this may have meant that other relevant material was missed, which would have been identified through wider searches. It seems likely however that most high quality systematic reviews would be published in a peer-reviewed journal, so this may be less of a problem than when searching for primary evidence. Thirdly, only English language papers were included, and one further review could not be obtained (Igna, 2011), leading to the exclusion of 19 potentially relevant items. It is likely at least some of these items may not have met the overview's inclusion criteria. Furthermore, the significant duplication of material in the included reviews, and the consistency of the abstracts of the excluded items with this material, suggests that it is unlikely that further reviews would have substantially altered the findings of this overview.

The greatest limitation of this overview is probably the limited quantity and, in many instances quality, of primary data on which the included reviews are based. This, together with the variable quality of the reviews themselves, clearly impacts on the reliability of their findings, and consequently those of the overview. This has partly been addressed by considering only RCT evidence and formally assessing the reviews' quality. The use of these rigorous methods means the findings of this overview are inevitably more circumscribed, but greater confidence can be placed on them. Areas where further research is needed also become more apparent.

3.2.5   Conclusion

On the basis of the current evidence, it seems likely that people with most LTC could potentially see some benefit from MMBIs, especially with regard to their mood and coping. These interventions may therefore be particularly helpful to people who are struggling emotionally with their condition, or who have mental health problems. The evidence for changes in depression is particularly strong and as this is often a co-morbidity with LTC (Galante et al., 2013) as well as a primary condition for many people, MMBIs may be of particular value in this respect.

Findings from the reviews suggest many experience significant changes on a range of psychological and psychosocial measures. The evidence suggests that the greatest change may be in people's relationship to their condition, rather than an objective improvement in the condition itself. The exact ways and degree to which people benefit appears to be variable and complex, leading some to question whether existing outcome measures fully identify their effects (Mars and Abbey, 2010). Similarly the factors which contribute to this variation are not yet fully understood, including the different ways MMBIs may be of value in different conditions, the relative importance of different aspects of the intervention, and the relationship between home mindfulness practice and outcomes. Such questions cannot be satisfactorily explored through RCTs, prompting Cramer et al to observe that *"[t]he existential changes that may result from participation in a MBSR program might be better addressed using qualitative approaches"* (2012b, pE351). The recognition of the need to explore the complexities of individuals' experience of mindfulness in order to fully understand its effects (Chiesa, 2013) has led to the publication of a significant number of qualitative and mixed methods studies, and these will now be explored.

3.3   Review of qualitative research

3.3.1   Identification and overview of qualitative studies

Relevant qualitative studies for this literature review were identified using searches based on the strategy developed for the overview outlined in 3.2.1.2. The same databases, excluding the Cochrane Library, were searched; however no date limits were set, as all participants' experiences were considered relevant. Details of the interventions were often limited, and standard programmes had frequently been adapted to varying degrees. This made it difficult to determine whether studies met the inclusion criteria, and contact with authors was made where necessary to clarify programme and population details. My

decisions regarding inclusion were based on whether the content of the intervention seemed to have been adapted to the extent that the adaptations substantially changed the experience of participants. Screening of identified records led to the identification of 23 relevant studies as shown in Figure 3.4.

Figure 3.4 Flow diagram for qualitative research review

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┌─────────────────────────────┐
│   1838 records identified   │
│  through database searches  │
└─────────────────────────────┘
              │           ┌──────────────────────────────┐
              ├──────────▶│   575 duplicates removed     │
              ▼           └──────────────────────────────┘
┌─────────────────────────────┐
│ 1263 records screened by title │
│        and abstract          │
└─────────────────────────────┘      ┌──────────────────────────────┐
              │                       │   1213 records excluded:     │
              │                       │  • Not in peer-reviewed      │
              ├──────────────────────▶│     publication              │
              │                       │  • Not qualitative research  │
              │                       │  • Not using a MMBI          │
              ▼                       │  • Not adults with LTC       │
┌─────────────────────────────┐      └──────────────────────────────┘
│ 50 records selected for review │
│        of full paper         │
└─────────────────────────────┘      ┌──────────────────────────────┐
              │                       │    27 records excluded:      │
              │                       │ 14  Not using a MMBI         │
              ├──────────────────────▶│  6  Wrong population         │
              │                       │  1  Not in English           │
              ▼                       │  6  Unable to retrieve full paper │
┌─────────────────────────────┐      └──────────────────────────────┘
│   23 records included in     │
│      literature review       │
└─────────────────────────────┘
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Included studies were of varying quality, depth and focus. Reflecting the increasing interest in mindfulness, only two were published prior to 2004, 11 from 2005-2009 and another 10 since 2010. Interestingly, and in contrast to the quantitative research, the majority (14, 61%) of the qualitative studies were published in the UK, with only six (26%) from North America and three (13%) from other parts of Europe. Participants with a range of mental health problems formed the focus for around half (12, 52%) of studies, with cancer being the next largest group (4, 17%). Two explored musculoskeletal conditions, two were with mixed populations, whilst there were individual studies with Parkinson's disease, cardiac rehabilitation and PTSD. Almost all studies based their research on either MBCT (12, 52%) or MBSR (9, 39%), at least over one-third had adapted the intervention to meet the needs of the particular population. Although MBCT was particularly developed for depression, it was used in a number of studies with other populations. Notably, all the MBCT studies were undertaken in the UK (where it was developed) or Europe, and it would appear to be being increasingly used in a similarly generic way to MBSR in North America, where the latter was the only intervention studied.

Most studies (18, 78%) used semi-structured interviews of varying length and depth to collect data. Others used focus groups (4, 17%), questionnaires (2) and diaries (1), with two using a combination of approaches. Analysis was informed by a variety of methodological approaches including phenomenology (8, 35%), thematic analysis (6, 26%), content analysis (6, 26%) and grounded theory (GT) (4, 17%); two studies noted using more than one approach. Depending upon the approach used, sample size varied considerably from three to 92 participants; 11 (48%) studies had up to ten participants, 7 (30%) 11-20 and the remaining 5 (22%) over 21. The experience of a total of 385 participants was included.

Not all studies provided demographic information; of those that did, 71% of participants were women, largely due to a number of studies of gender-specific conditions, particularly breast cancer. Similarly, reflecting the prevalence of conditions such as schizophrenia, obsessive-compulsive disorder and cardiac problems in men, studies of these populations had greater proportions of male participants. Where the information was provided, participants were predominantly white and of above average educational level, although a few studies targeted disadvantaged and ethnic communities. Ages varied considerably, to some degree reflecting the conditions studied and increasing prevalence of LTC with age; a few deliberately focused on particular age groups.

Data were collected at a variety of time points relative to the intervention, with some studies having multiple time points before, during and after participation. Not all studies clearly identified the timing, but of those which did, the majority explored people's experiences immediately after or within 3 months of participation (14, 61%). Five (22%) had a time point of up to one year, whilst three studies (13%) looked at longer term experiences.

3.3.2 Synthesising qualitative research findings: a meta-ethnography

Although less well established than systematic reviewing, there is increasing recognition of the value of drawing together the insights and findings from different qualitative studies into the same phenomenon through a process of qualitative synthesis. Individual studies are inevitably small scale, and many studies fail to reference each other, which can lead to their findings being lost (Campbell et al., 2011). Sandelowski notes that *"qualitative research […] appears endangered by the failure to sum it up"* (1997, p366), and qualitative synthesis provides a means to create a weight of evidence around the experience of a particular phenomenon (Campbell et al., 2011). A number of approaches can be taken, including meta-ethnography which aims to explore the connections and overarching processes present in people's experiences across a number of studies. Meta-ethnography aims to develop new understandings of the phenomenon being studied rather than simply provide an overview of what is already known. In the same way that more abstracted themes are identified from individuals' experiences through approaches such as grounded theory (GT), meta-ethnography generates new concepts from qualitative studies which are 'greater than the sum of the parts' and offer new interpretations of the data as a whole.

Qualitative synthesis assumes that there are aspects of experience which resonate beyond the individual study context, but this has to be balanced by the recognition that the

context of qualitative studies is a key element in establishing their credibility. There is therefore a challenge in *"carefully peeling away the surface layer of studies to find their hearts and souls in a way that does the least damage to them"* (Sandelowski et al., 1997, p270). Meta-ethnography is based on an interpretive framework, and thus recognises the importance of context and meaning, using a process of 'translation' to explore the relationships between studies. The need for concepts to be grounded in the data is emphasised, as is the need for them to be communicable and credible to a wider audience (Campbell et al., 2011).

In the early stages of my research, consideration was given to undertaking a synthesis of the qualitative research of mindfulness experiences. During the course of the research however, Malpass et al published their paper, *"Transforming the perceptual situation: a meta-ethnography of qualitative work reporting patients' experiences of mindfulness-based approaches"* (2012), which reviewed a body of work almost identical to that being considered for my study. As a result, the next section begins by exploring and critiquing this meta-ethnography and then identifies additional relevant qualitative studies, considering their findings in relation to it.

3.3.3   Review of the meta-ethnography

Qualitative synthesis is a relatively new approach and involves a considerable amount of complexity which makes it difficult to standardise (Campbell et al., 2011); as a result there are no established tools for quality appraisal. As meta-ethnography contains elements of both qualitative research and systematic reviewing, appraisal tools relevant to these research strategies were drawn on in order to provide a framework for reviewing Malpass et al's work, in particular the CASP tool for appraising qualitative research (CASP, 2006) and the AMSTAR systematic reviewing tool (Shea et al., 2009). Two main aspects of the paper were explored: methods and findings.

3.3.3.1   Methods

Malpass et al's work offers the first synthesis of qualitative work into experiences of mindfulness. They identified a clear aim: *"to derive an overarching narrative of patients' experiences of the process and perceived benefits of mindfulness"* (2012, p61).   A subsidiary aim was to explore whether the same processes are experienced by different populations and conditions and across different mindfulness approaches. Meta-ethnography was considered to provide an appropriate method to address these questions due to its ability to generate new insights into the existing studies. Noblit and Hare's seven stage process was outlined (1988), and a clear description was given of how these were carried out. Full details of search criteria and strategies were provided, although no dates for the literature searches were given. These would seem to have taken place during 2010 as this was the latest publication date included.

The inclusion criteria were outlined and issues concerning applying these criteria were highlighted, particularly the difficulty of determining the degree of variation in the intervention which should be included. Decisions regarding intervention and population closely reflected those used in the literature review for this thesis (here termed 'my

review' for clarity and simplicity), but differed in a few notable respects. Malpass at al identified MBSR and MBCT as the included interventions, and also included modified versions of these courses where the changes had been clinically justified. This in one case led to their inclusion of a 20 week course (Moss et al., 2008) which was excluded from my review because of its length. Their work focused on *"the patient experience"* (Malpass et al., 2012, p61), and so generally excluded non-clinical populations but inexplicably included one study (Kerr et al., 2011) with a group of healthy females. Finally, no age restrictions were applied, and a study of HIV-positive youth aged 13-21 (Sibinga et al., 2008) was therefore also included. Thus, of their 14 included papers, three did not meet my inclusion criteria. A list of excluded papers was not provided, so it was not possible to ascertain which other studies had been considered.

Apart from much of the initial screening (where only a subset of titles and abstracts was jointly reviewed), most stages of study selection and appraisal, including the identification of the constructs within each paper, were undertaken by more than one person to ensure consistency. No details were given of how any disagreements were resolved. The subsequent translation of constructs was denoted as a joint process by use of the term 'we', but no details were given of who was involved. There was also no information about the background and skills of team members, which would have provided valuable insight into the perspectives and contributions each were offering.

A clear critical appraisal strategy to rate each paper was described although, apart from identifying the key papers, no details were provided of the rating given to each study. An intention to consider the difference in findings when only the key papers were included was noted, but the outcome of this was not clear. A reference map to explore the relationships between studies was also referred to but not included. Two of the four key papers did not meet my inclusion criteria (Sibinga et al., 2008, Moss et al., 2008). To establish the contribution of these papers to the findings, I reviewed the meta-ethnography's final list of translated constructs and their sources. This revealed that all the constructs remained even when these two papers were omitted. On this basis it seemed appropriate to consider Malpass et al's (2012) findings wholly relevant to my review, and these are presented and critically appraised in the next section.

3.3.3.2 Findings

Included studies were published between 2001 and 2010, and their characteristics reflected those of the broader group of studies discussed above. Findings were drawn from a total of 170 people. Most included studies were entirely or largely based on data gathered within three months of attending the mindfulness course, with only four including follow-up of one year or more. Perhaps as a result of this short term focus, the meta-ethnography focused on the transition process that participants described as they initially engaged with mindfulness and integrated the thinking and practices into their lives. Malpass et al (2012) noted that this process appeared to be common to all included conditions and interventions.

Three phases were identified, by which patients moved from *'perceived safe certainty'*, through *'safe uncertainty'* to *'grounded flexibility'*, terms based on Moss et al's key paper (2008). In phase one, participants were exposed to themselves, and became aware of

their existing habits and patterns. In the second phase, skills in maintaining present moment awareness were developed, although challenges in learning to think and act in new ways were also identified. A change of perspective, a 'stepping back', took place at this stage, and this was continued in the third stage which saw a transformation of the relationship to illness and the sense of self. Malpass et al acknowledged the on-going movement between these phases as individuals' circumstances change.

The three-phase model was further developed by drawing on the concepts from the translation process to produce a more complex and detailed model of *"the experience of the therapeutic process in mindfulness"* (Malpass et al., 2012, p68). **Phase one** encompassed recognition of past patterns of ignoring or lacking awareness of present moment experience, and engagement with the difficult task of turning towards and coming to terms with this experience. *Letting go of striving* for particular outcomes from mindfulness yet *being open to change* were identified as key processes enabling this phase to happen. The key process in **phase two** was termed *"transforming the perceptual situation"* (Malpass et al., 2012, p68), drawing on Shapiro et al's concept of re-perceiving (2006), through which the ability is gained to observe one's experience rather than be entirely identified with it. This transformation was facilitated by four therapeutic processes: *dis-identification and stepping back from experience*; *facing the difficult with kindness*; *learning to focus attention on the present moment*; and *being able to take a wider perspective* encompassing both pleasant and unpleasant aspects of experience.

Phase three was characterised by a transformation in the relationship to the illness experience and in the sense of self. Four benefits were associated with this phase; highlighting the difficulty of separating process from outcome in the mindfulness experience, these were also aspects of the processes identified in phase two. An increased *self-awareness and sense of control* enabled new responses to stressful situations, including dis-identification and letting go, thus facilitating self-regulation. Greater *acceptance and kindness* towards self and illness enabled improved self-care. This was also supported by a *sense of command* which resulted from increased awareness of early symptoms and having new ways to calm the mind and body. An increased sense of agency was also noted, with participants gaining *flexibility and choice in* their response to their illness or difficulty. The considerable interconnection between these benefits made them difficult to clearly distinguish, or to separate from aspects of phase two. There was also an overlap with what was depicted as the culmination of the process, the transformation in the relationship to inner experience. This was marked by a change of perspective on a broader level, characterised by a new outlook on life and new sense of self. In particular, the emergence of an *"observing self"* (Malpass et al., 2012, p71) was identified, which changed how people related to the whole of their experience, including their illness.

The value of the group in supporting change was emphasised. It helped reduce isolation, normalised the illness experience and mindfulness practice, and offered support and motivation with making changes in life. A number of challenges were also identified, including discomfort with the meditations and lack of understanding of mindfulness. These sometimes led to a sense of failure and self-judgement, particularly where participants held onto particular goals of practice.

Whilst the meta-ethnography clearly outlined how mindfulness provided a new way of relating to experience, and identified the various elements which facilitated this, some aspects of it were not entirely clear. As noted above, there was considerable overlap between aspects of phases two and three, which made them difficult to differentiate. In addition, some of the terminology used did not seem to support or clarify their model. In particular the terms for the three phases, 'perceived safe certainty', 'safe uncertainty' and 'grounded flexibility', did not seem to clearly relate to or communicate the essence of the experience being described at each stage. Some of the language, such as *"transforming the perceptual situation"*, was also perhaps unnecessarily complex, and as a result lacked immediacy or communicability. The diagrammatic representation of the process was helpful but quite complex, and the relationships between the different aspects were difficult to interpret without a careful reading of the text. Thus, although the process appeared comprehensive and credible (there were many quotes from the individual studies to support it), I found it difficult to readily recall or describe. Campbell et al (2011) suggest that one aspect of the quality of a meta-ethnography is the adequacy of its metaphors or concepts, emphasising that they should be simple, cogent, and communicate clearly in a way which has meaning beyond the immediate context. It was in this respect that this work could have been developed to communicate its findings more vividly and effectively.

As noted earlier, the meta-ethnography predominantly focused on the initial transition from a non-mindful to a mindful approach to illness and self, and did not explore how this process may continue to evolve over time. The authors also briefly considered how the findings relate to wider literature around illness and identity, drawing particularly on one team member's work on 'behavioural plasticity' (Carel, 2009). This identifies how people learn to adjust to their illness through living in the present and recognising the transient nature of life, attitudes identified in the meta-ethnography as essential aspects of mindfulness. Carel suggests that people develop the ability to shift illness between the foreground and background of experience, an idea explored by other writers on chronic illness (Frank, 1995, Paterson, 2001b). As these points were only briefly considered, there remains a need for further exploration of how mindfulness can inform understanding of wellbeing within illness.

In its final section, Malpass et al considered how their findings may inform the discussion about mechanisms of mindfulness, and how the processes identified in the meta-ethnography relate to different proposed models, in particular the work of Baer (2009) and Shapiro et al (2006). They note that Baer's three mechanisms of increasing familiarity with negative experience, controlling the focus of attention and cultivating non-attachment were clearly represented in the meta-ethnography, whilst two of Shapiro's three axioms, attention and awareness, seemed to be more central than the third, intention. Other models were also explored briefly, and a link between the therapeutic processes in stage two and Teasdale's model of meta-cognition was considered (1999). This is a particularly complex idea which did not seem well integrated into the rest of the discussion, and it was therefore difficult to judge its value.

Overall, this meta-ethnography makes a valuable contribution to the research base by identifying that there are a number of strong common experiences across the qualitative

literature which are unrelated to health condition or, certainly for MBSR and MBCT, to intervention. It outlines how through mindfulness, participants experience a process of change and transformation in their relationship to themselves and their illness which is challenging but brings significant benefits. This process appears to have a number of phases and elements, some aspects of which form both facilitators and outcomes of it, highlighting both the complexity of the mindfulness experience and its potentially self-reinforcing nature.

In the next section, further relevant material not included in Malpass et al's work is explored to identify how it develops and refines the findings of the meta-ethnography.

3.3.4   Review of other relevant qualitative literature

As noted in 3.3.1, searches identified 23 relevant qualitative studies. The meta-ethnography's inclusion criteria overlapped substantially with those used for these searches, as highlighted in 3.3.3.1. As a result, 11 of the 23 studies had been incorporated into the meta-ethnography, leaving an additional 12 studies to review. Nine have been published during or after 2010, presumably since the searches for the meta-ethnography were undertaken (assumed to be early 2010 from the dates of included publications), whilst three were assumed to have not to have met inclusion criteria or not been identified for the meta-ethnography (the absence of information regarding excluded papers makes this impossible to determine).

Characteristics of included studies are shown in Figure 3.5. The studies were reviewed for methodological and reporting quality using the CASP tool (CASP, 2006), and quality scores are shown in Figure 3.6. As with the systematic review quality assessment, scoring was adapted to recognise partial meeting of criteria, and scores allocated to three bands reflecting levels of confidence in the study's findings. Quality varied considerably, with only four studies scored as high quality. As with the overview, lower scores may have been a result of inadequate reporting of methods, possibly due to publication word limits. There was frequently little reflexivity concerning the impact of the researcher on the process, and some studies provided limited discussion of findings in terms of their integration with other research. It was of note that most of the lower scoring studies were part of larger predominantly quantitative evaluations of mindfulness interventions, and had therefore not been designed to meet the criteria for qualitative research or may have reported aspects of their methods elsewhere.

The key themes in each study were identified and explored using mind maps. These findings were then considered in the light of the meta-ethnography, particularly noting areas of similarity and difference. (The meta-ethnography itself was not referred to by any authors, perhaps being published too recently for this to be possible.) From this process it quickly became clear that regardless of study quality or methodological approach, the themes and findings were strongly consistent with Malpass et al's three-phase model (2012), with identical language used for many terms and processes.

Figure 3.5 Characteristics of additional included qualitative studies

Author	Country	Year	Inter-vention	Population	Participant numbers (and characteristics)	Data collection method	Data collection time points	Methodological approach
Majumdar et al	Germany	2002	MBSR	Chronic physical and/ or stress complaints	21 (17 women, above average education level)	Interviews (part of mixed methods evaluation)	Pre, post and 3 months after course	Content analysis
Proulx	USA	2008	MBSR adapted	Bulimia nervosa	6 (all women, college age)	Interviews and self-portraits	Pre and post course	Interpretive phenomenological analysis (IPA)
Cebolla and Barrachina	Spain	2009	MBCT adapted	Anxiety, depression	32	Questionnaire (part of mixed methods evaluation)	Post-course and 3 months after	Content analysis
Brown et al	USA	2010	MBSR adapted	Anxiety in schizophrenia	15 (all older men, 40% African American)	Interviews	Mid and post-course	Content analysis
Hawtin and Sullivan	UK	2010	MBSR	Rheumatic disease, various	5 (4 women)	Focus groups	6 months after course	IPA
Chadwick et al	UK	2011	MBCT adapted	Bipolar disorder	12 (5 women)	Interviews	At least 18 weeks after	Thematic analysis
Langdon et al	UK	2011	MBCT	Mixed physical and mental health	13 (10 women)	Interviews	3 months - 5 years after course	GT
Williams et al	UK	2011	MBCT adapted	Hypochondriasis (health anxiety)	9 (7 women)	Interviews (part of RCT)	3 months after course	IPA
Hertenstein et al	Germany	2012	MBCT adapted	OCD (obsessive compulsive disorder)	12 (3 women)	Interviews	At course completion	Content analysis
Hofmann et al	UK	2012	MBSR	Breast cancer	92 (all women)	Questionnaire (part of RCT evaluation)	At course completion	Content/ thematic analysis
Bermudez et al	USA	2013	MBSR adapted	PTSD, domestic violence	10 (all women, mostly non-Caucasian	Interviews (part of RCT)	Pre, mid, post and 3 months after course	IPA
Dennick et al	UK	2013	?MBCT adapted	Distressing psychosis	3 (1 woman)	Interviews	Unclear	IPA

Differences were also noted, however. Reflecting their methodological approach, most papers did not explore participants' experiences as a process, with only Langdon et al (2011) developing a model of mindfulness practice over time; this is discussed further in 3.3.4.4. The meta-ethnography's broad overview inevitably did not identify condition-specific aspects of experience and the additional papers, particularly the higher quality studies, provided valuable insights in this respect. Additional dimensions of experience were also identified. These correspondences and differences will now be discussed.

Figure 3.6 Quality rating for additional included qualitative studies

Author & year	Population and intervention	Quality rating*
Chadwick et al 2011	Bipolar disorder, MBCT	+++
Hertenstein et al 2012	Obsessive compulsive disorder, MBCT	+++
Proulx 2008	Bulimia nervosa, MBSR	+++
Williams et al 2011	Severe health anxiety, MBCT	+++
Bermudez et al 2013	PTSD, domestic violence, MBSR	++
Brown et al 2010	Schizophrenia, anxiety, MBSR	++
Cebolla & Barrachina 2009	Anxiety, depression, MBCT	++
Dennick et al 2013	Distressing psychosis, MBCT	++
Hawtin & Sullivan 2010	Rheumatic diseases, MBSR	++
Hofmann et al 2012	Breast cancer, MBSR	++
Langdon et al 2011	Physical & mental health, MBCT	++
Majumdar et al 2002	Chronic physical and/or stress complaints, MBSR	++
* Quality scores : + = 0-4.5; ++ = 5-7.5; +++ = 8-10		

3.3.4.1   Correspondences with the meta-ethnography

As noted previously, phase one of Malpass et al's model focused on participants' challenges in facing painful aspects of their experience through mindfulness, whether looking at the reality of their condition or recognising unhelpful patterns of behaviour. A number of studies echoed this theme, and identified the ongoing struggle to engage mindfully with life's difficulties (Brown et al., 2010, Chadwick et al., 2011, Hoffman et al., 2012, Bermudez et al., 2013). Many also emphasised the important role of the group in this initial stage in supporting, accepting and validating participants' experiences. This in some instances would seem to have been as important as mindfulness practice itself in people's experience of change (Proulx, 2008, Dennick et al., 2013).

The progressive change in perspective, which characterised both the second and third phases, was strongly supported by the additional papers although, as noted above, aspects of these phases significantly overlap. The four therapeutic processes associated with phase two appeared frequently, although to varying degrees. The ability to step back and observe experience from a more dis-identified perspective featured strongly, and was closely linked to a greater sense of self-awareness and self-regulation, which Malpass et al located in phase three. Participants described learning to pause and choose their response to different situations rather than simply reacting in habitual or impulsive ways which were often unhelpful or self-destructive; these included binge-eating, obsessive rituals and emotional reactivity (Proulx, 2008, Hertenstein et al., 2012, Bermudez et al., 2013).

Participants' increased awareness of their patterns of thinking and acting also provided insights which enabled them to make positive changes, which in turn increased their sense of agency and control. This feeling was particularly evident with anxiety-related conditions such as obsessive compulsive disorder (OCD) (Hertenstein et al., 2012) and hypochondriasis (Williams et al., 2011), and in a group with distressing psychosis (Dennick et al., 2013). A further result of greater awareness was people's improved ability to notice changes in their symptoms, particularly low mood, and take action to prevent escalation (Chadwick et al., 2011, Hawtin and Sullivan, 2011), an outcome located in phase three of the meta-ethnography. Notably, a high-quality study of people with severe health anxiety found that greater awareness of bodily sensations did not produce an escalation of anxious thoughts and feelings, as frequently occurs with this condition (Williams et al., 2011). This finding suggested that although awareness increased, this was accompanied by less reactivity due to the non-judgemental nature of mindfulness.

A second strongly supported theme was the ability to focus on the present moment, which helped avoid rumination and anxiety. In a study of people with schizophrenia this, through meditation, provided a valuable 'anchor' in relation to their hallucinations and dreams (Brown et al., 2010), whilst the image of an anchor was also used by women with PTSD following domestic abuse (Bermudez et al., 2013). Directing attention to present moment experience also frequently increased people's appreciation of their surroundings and life. Whilst this was of value in many situations, Chadwick et al (2011) highlighted how this may be particularly important for people with bi-polar disorder where high mood states may otherwise seem more attractive than everyday life. Directing attention towards the present moment also helped distract from difficult thoughts and feelings, although Hawtin and Sullivan (2011) noted the difficulty of distinguishing between positive attention control and non-mindful avoidance of unpleasant experiences.

A focus on the present moment increased people's awareness of the transience of difficult experiences and emotions (Hertenstein et al., 2012, Bermudez et al., 2013) and aided the recognition that thoughts were not facts (Chadwick et al., 2011), another aspect of the dis-identification process discussed above. This changed perspective in turn increased people's capacity to tolerate difficult thoughts and sensations and reduced reactive behaviour linked to struggling to change things (Hawtin and Sullivan, 2011, Hertenstein et al., 2012). These experiences seemed to combine the meta-ethnography's phase two process of *facing the difficult* with the outcome of *a sense of command* in phase three. They also linked to the fourth process in stage two, becoming bigger than experience and looking at things differently. Some aspects of this process were present in the additional papers, particularly the idea of developing an 'observing self' (Proulx, 2008) and feeling less overwhelmed by illness (Hawtin and Sullivan, 2011, Dennick et al., 2013). One aspect, being able to hold all aspects of experience together, was not specifically mentioned.

A strong theme in the additional papers, which forms one of the outcomes associated with stage three, was acceptance and kindness. Acceptance of self and experience was noted by Hertenstein as the distinctive feature of mindfulness compared to other interventions (2012), and frequently had an important role in the process of change. It contributed to reducing the sense of struggle, and allowed people to view their situation more clearly and realistically. An important aspect highlighted by some papers was the reduced sense of

shame and guilt that people experienced about themselves and their condition, which could otherwise trigger further episodes. This was noted in relation to both bipolar disorder (Chadwick et al., 2011) and OCD (Hertenstein et al., 2012). Hoffmann described women with breast cancer feeling more 'at home with themselves' (2012), whilst women with eating disorders recounted a greater sense of connection to their bodies (Proulx, 2008). This greater ease and acceptance helped people to know and understand themselves better, and gave them permission to value and care for themselves more effectively, such as by taking time out or feeling able to communicate their needs to others (Cebolla and Barrachina, 2009, Bermudez et al., 2013). Hoffman et al emphasised the pivotal role of *"making time and creating space for myself"* (2012, p225) in improving participants' ability to self-manage.

Acceptance, particularly as it was demonstrated and experienced within the group setting, was key in enabling some people to construct or reclaim a more positive sense of themselves which had sometimes been lost through the experience of illness. This latter point was particularly noted in studies of psychosis (Dennick et al., 2013) and binge eating (Proulx, 2008), both conditions with considerable stigma attached. Mindfulness practice and the group experience enabled people to feel more empowered and confident in their lives, and less affected by others' judgements. This change was integral to the third stage of Malpass et al's model, where the culmination of the process was seen as a transformation of the relationship to illness and self and the restoration or creation of a new sense of self.

3.3.4.2   Additional themes: a) Changed relationships

One outcome apparent in the additional papers that did not appear in the meta-ethnography was how mindfulness, and acceptance in particular, impacted on participants' relationships with other people (Proulx, 2008, Cebolla and Barrachina, 2009, Hoffman et al., 2012, Bermudez et al., 2013). Increased confidence and assertiveness enabled people to improve their communication, whilst reduced reactivity and greater acceptance gave them greater tolerance of others' limitations and failings. Participants also noted a greater sense of universality, moving from feeling isolated to recognising common ground and connection with others (Dennick et al., 2013). This in turn enabled them to better listen to and take account of others' needs.   These changes were often also noticed by others, prompting changes in their own behaviour and thus further improving the relationship.

This experience was particularly evident in studies of women who had experienced domestic violence and trauma (Bermudez et al., 2013), and young women with eating disorders and self-harm (Proulx, 2008). Participants described being able to connect more positively with themselves and to form trusting and compassionate relationships with others. Similar changes were also identified three months after training in a lower quality study of people with anxiety and depression, where MBCT was adapted to incorporate additional material to enhance mindfulness in inter-personal relationships (Cebolla and Barrachina, 2009). The authors noted the increasing recognition of the role of compassion within mindfulness interventions. This would appear to be particularly important where difficult intra- and inter-personal relationships are the primary area of suffering, but was also relevant to many people with LTCs, who felt isolation and low self-esteem due to their

illness. This dimension of experience i.e. changed relationships, could be usefully incorporated into Malpass et al's model of change, a point emphasised in a qualitative study completed since this literature review was carried out (Bihari and Mullan, 2014).

3.3.4.3 Additional themes: b) Improved symptoms

Whilst the meta-ethnography focused on the transformation of people's perceptions of their illness and self, it is worth noting that a number of participants also experienced changes in their symptoms, a difference which was corroborated by quantitative findings in the mixed methods studies. The additional papers mentioned a range of changes, including alterations in pain, sleep and mood, including less stress and anxiety and greater optimism. Many people reported greater calm, peace, ease and relaxation, whilst more condition-specific changes were also noted, such as improvements in concentration and memory, and reduced paranoia and mood swings. These changes were generally sustained, although there is limited information about this due to the paucity of studies with longer-term follow-up. It is significant that there were no reports of aggravation of symptoms from mindfulness practice, although this was considered a potential risk in studies of schizophrenia (Brown et al., 2010) and hypochondriasis (Williams et al., 2011).

3.3.4.4 Additional themes: c) Engaging with mindfulness practice

A final aspect of experience not explored in the meta-ethnography to any significant depth concerned participants' accounts of their engagement with the course and mindfulness practices. These were not included in Malpass et al's model, which focused on changes in participants' relationship to their illness. As they were frequently referred to in the additional papers however, sometimes forming a key theme, these experiences need to be mentioned here.

Most participants found the intervention acceptable, and engaged positively with mindfulness, with the large majority committed to continuing practice after the course. Negative experiences generally related to individuals finding that mindfulness did not meet particular expectations around relief of difficult or distressing symptoms. People's struggles with the mindfulness however, particularly in the early stages, were highlighted by a number of studies. Some of these were generic difficulties, including scepticism, trying to change habits, and a struggle to 'get it right' which sometimes led to a sense of frustration and failure. In addition, more condition-related problems were also apparent. Although pain was mentioned in this context, most of these difficulties related to mental and emotional challenges such as anxiety and intrusive thoughts (Cebolla and Barrachina, 2009), depression (Chadwick et al., 2011) or psychotic episodes (Brown et al., 2010). In contrast to Malpass et al's description of increasing difficulties during the course, most problems noted here resolved as the course progressed, but some remained as ongoing challenges to practice.

The tension between the desire to integrate mindfulness into life and the struggle to do so was a common theme, and was explored in depth in Langdon et al's GT study of a diverse population with up to five years' experience of working with mindfulness practice (2011). Although some aspects of the methods in this study were not clearly reported, the longer time period since attendance had enabled the development of a theory and model of the

journey of mindfulness which offered valuable insights into the way that people move in and out of practising. Three phases were identified: a virtuous cycle of practice; slipping out of the cycle and reducing practice; and returning to practice. Movement between these phases was seen to happen repeatedly and was influenced by both internal beliefs and experience and by external events and other people. Each phase also had cyclical elements that served to create either virtuous or vicious circles of experience which maintained the existing situation. For example, experiencing the benefits of mindfulness was likely to provide motivation to continue practising, whilst a frustration with oneself for *"slipping out of the cycle"* (Langdon et al., 2011, p275) could lead to a lower mood which further reduced practice.

The diversity of patterns of practice was also explored by other studies, although the generally shorter time since course attendance prevented conclusions being drawn about whether these were sustained. The range of practices taught enabled people to select what they found most beneficial, with shorter meditations often considered particularly helpful. Two studies (Cebolla and Barrachina, 2009, Williams et al., 2011) noted how participants either used meditation as a tool in times of difficulty, or adopted a regular practice which they considered a way of life. Others highlighted how participants adapted practices to their own needs, with Chadwick's (2011) high quality study in particular exploring how a group of bi-polar participants found different styles of mindfulness practice helpful at different phases of their illness.

3.3.4.5 Longer term changes

As in the meta-ethnography, most of the studies focused on participants' experiences either immediately after or within a few months of attending the course, so there was little opportunity to understand more about the long-term experiences of mindfulness. One exception was Bermudez et al (2013), who explored participants' experience at four time points over 15 months from the start of the course, and noted some continuation and deepening of experience, including implementing mindfulness skills in life. The data were not however presented in a way that enabled changes to be associated with particular time points. Only Langdon et al (2011) explored a longer time period of up to five years but, as discussed above, this study focused on patterns of mindfulness practice rather than changes in people's experience of living with their condition.

3.3.5 Summary of qualitative research findings

A significant body of qualitative research into people's experiences of mindfulness training and practice now exists, and this has expanded at a rapid rate over the past few years. Studies are based on a range of interventions, which have often been adapted from their standardised format to meet the needs of particular groups. This flexibility is a strength of the interventions, but also presents challenges in terms of identifying the role of specific elements and determining relevant outcomes. Qualitative methods have enabled some of these challenges to be addressed. A diverse range of populations with LTCs have been studied; participants have been predominantly white and of above average educational levels.

Despite this variation, and the range of qualitative approaches used, a consistent picture of people with LTCs' experience with mindfulness seems to be emerging. This was evidenced in Malpass et al's (2012) meta-ethnography of 14 studies, which has developed a three stage model of the therapeutic process of mindfulness. Participants appeared to undergo a transformation in their relationship to their illness and to themselves, which enabled them to view their experience with greater acceptance and from the perspective of an 'observing self'. This for many was a significant change from being overwhelmed and diminished by their illness, and had an impact on many aspects of their lives.

The findings from the meta-ethnography were confirmed by the 12 additional papers included in my review, the majority of which have been published since its publication. Echoing Malpass et al, findings were consistent across populations, interventions and methodological approach. Whilst many common patterns of change were apparent, these studies also provided an opportunity to identify the ways in which the outcomes of mindfulness training and practice were nuanced to the needs of different populations. This would seem to be a result not just of the adaptations made to the intervention, but due to people experiencing mindfulness as relevant to their particular physical, mental and emotional difficulties. This is exemplified in a study of women with post-traumatic stress disorder, which noted that although the course did not directly address these issues, *"participants applied the skills and knowledge to overcoming past traumas"* (Bermudez et al., 2013, p107). The additional papers also highlighted changes in actual symptoms as well as in perspective, and drew attention to an additional significant theme of greater connection and improved relationships with other people.

Findings from the qualitative research were strongly positive across all conditions, with the few instances of individuals not finding it helpful mostly relating to particular expectations of improvement not being met. Many participants however found aspects of mindfulness challenging; this applied to both learning to face difficulty and struggling to integrate mindfulness into life. The process of engaging with mindfulness practice was not explored within the meta-ethnography but Langdon et al's (2011) model of moving in and out of practice encapsulated the struggles described in a number of studies. Others highlighted the different ways in which participants selected and adapted practices to meet their own needs. From her perspective as a clinician, Hawtin (2011) observed that the experiences of those who find mindfulness difficult or ineffective and discontinue practice is generally not reflected in qualitative studies.   There is a need for more research with this group, but this presents challenges as they generally do not respond to invitations to participate in studies.

Most studies explored participants' experiences within a few months of attending training, although the limited amount of longer term follow-up indicated that many people continued to practice and gain benefit. This suggests that there is a need for more in-depth exploration of the long term experience of mindfulness and of how it affects people's perception and ways of living with their condition. In addition, although Malpass et al made some links with the extensive literature regarding the chronic illness experience, the relationship of mindfulness to existing understandings of how people come to terms with living with a LTC needs to be more fully explored.

3.4 Chapter summary and research question

In this chapter, the empirical evidence for the effects of MMBIs on people with LTCs has been reviewed. The systematic review identified strong evidence for MMBIs positively impacting on depression relapse rates and improving mental and emotional wellbeing of people with a variety of LTCs. The lack of trials with an active control group design prevented MMBI-specific changes being conclusively identified, but there was some evidence that a changed relationship to illness may be of more significance than direct improvement in particular symptoms. This finding was borne out in the qualitative research, where Malpass et al's (2012) meta-ethnography depicted a transformation in people's perception of their illness and themselves which affected their experience in a variety of ways. These strongly positive findings were echoed and further developed in additional qualitative studies largely published in the last three years.

Findings of the overview of systematic reviews and the review of qualitative research suggested that experiences of MMBIs were largely consistent across all conditions and interventions. The qualitative research also offered indications that participants' experiences and patterns of mindfulness practice had some condition-specific elements, although these variations and the factors which may contribute to them have not been comprehensively explored. Very few negative experiences were reported, but the challenges of integrating mindfulness into everyday life were frequently noted in the qualitative research. The overview however identified inconclusive evidence of the link between home practice and outcomes, and there is clearly a need for greater understanding of how ongoing engagement with mindfulness affects people's experience.

A number of other limitations to the existing research were also noted. In particular, most data related to people's experiences immediately after or within a few months of the intervention. There is a need for more exploration of the longer term effects of MMBIs, and of how people integrate mindfulness into their lives to achieve these effects. This may also highlight variations in experience between people with different conditions or different patterns of mindfulness practice which are not apparent in the short term. As noted in the overview, there are tentative indications of greater long-term benefit from MMBIs which need to be further explored, as these would be particularly significant to people with LTC who may not otherwise expect an improvement in their situation.

An extensive literature regarding chronic illness experiences already exists, and this was briefly considered by Malpass et al. There is a need to further embed mindfulness experiences in this literature, to identify how mindfulness may inform and be informed by the ideas developed in this field. Meditators may have a particularly valuable contribution to make to understanding living with a LTC; as Walsh and Shapiro note, *"their introspective sensitivity may make them exceptional observers of subjective states and mental processes"* (2006, p234). This may be even more true of mindfulness practice, with its focus on clear observation of present moment experience.

This in-depth exploration of the research into MMBIs therefore confirmed and developed the findings of the initial critical mapping exercise described in 3.1.1. Whilst identifying convincing evidence that people with a variety of LTCs experience psychological benefits in

particular from participating in MMBIs, it revealed a lack of knowledge of various aspects of this experience. Identifying these gaps in the literature led to the development of the research question for this study:

How does practising mindfulness affect people's experiences of living with a long-term condition?

A number of subsidiary questions were also identified:

- How do people understand and describe their experiences (positive and negative) of practising mindfulness as taught through Breathworks in relation to living with a LTC?
- In what ways and for what reasons do people with LTCs integrate mindfulness into their lives?
- How do people with LTCs perceive that practising mindfulness affects the way they relate to and manage their condition?
- In what ways are people's experiences similar, and how do they differ?
- Does the variation seem to relate to any identifiable characteristics e.g. condition, amount (e.g. frequency, length) of mindfulness practice, personal circumstances?

Whilst a considerable amount of both quantitative and qualitative research has been published since the research question was developed, the issues it addresses remain relevant. In addition, as most research into MMBIs has been based on MBSR and MBCT, the selection of Breathworks' mindfulness programme for this study provided an opportunity to explore the effect of a slightly differing intervention on participants' experiences, thus helping to clarify the degree of commonality in experience across the range of MMBIs. Attention now turns in the next two chapters to exploring the methodology and methods selected for addressing these questions.

Chapter 4
Methodology

4.1   Introduction

In chapter 3, a review of the literature highlighted gaps in existing knowledge of the effects of mindfulness which informed the development of the research question for this thesis. The next two chapters identify and explain my decisions about how this question could best be answered.   This chapter explores the rationale for the selection of my methodological approach and, as a key aspect of this, identifies my theoretical perspective and how this informs the research design. Chapter 5 then details the specific methods adopted within these frameworks.

I start by detailing my understanding of methodology and highlighting the importance of sound and transparent methodological choices. I then explore questions of ontology and epistemology in order to clarify my particular perspectives, identifying critical realism and interpretivism as most accurately reflecting my position, but also exploring the influence of feminist research on my work. In the light of this, I identify and explain the selection of a qualitative methodology for this study and in particular of a grounded theory approach informed by a constructivist perspective. Finally, questions of ethical practice and quality are considered, and how these have been ensured within the research.

4.2   Defining methodology and its role

Methodology can be defined as the overall design of the research to address the particular question or problem that has been identified, and the rationale behind that design (Williams and May, 1996). Creswell characterises methodology as a *"strategy of inquiry"* (2009, p5), identifying qualitative, quantitative and mixed methods approaches as potential options. The methodology selected for a study depends upon a variety of factors, including the purpose and context of the research, the nature of the research question, the type of object being studied, and upon the theoretical perspective of the researcher (Danermark et al., 2002, Snape and Spencer, 2003, Ritchie and Lewis, 2003). As Danermark et al note, methodology is the *"borderline between on the one hand the philosophy of science, and on the other hand the critical methods or working procedures used in specific studies."* (2002, p73). Study design is therefore fundamentally affected by the researcher's philosophical position and, in particular, by their epistemological and ontological perspective. These determine what the researcher considers it possible to know about a particular phenomenon and with what degree of certainty, and whether there is any objective reality to that phenomenon beyond what is experienced by those involved. These questions are considered in depth in the next section.

Sound methodological choices are fundamental to the integrity of the research process and to the credibility of the research findings. They provide the rationale and justification

for the selection of the methods used to carry out the research. These decisions also ensure that an appropriate *kind* of answer to a particular research question is obtained, and therefore also determine whether the 'answer' or findings can be considered valid and meaningful. To enable others to judge the value of a piece of research, it is therefore essential that methodological choices are made transparent, so that their consistency with the research question and the researcher's beliefs can be assessed. By identifying the underpinnings on which the research is built, it is possible to judge the soundness of what has been constructed upon them. To provide this transparency, the next section identifies my philosophical perspective. I then present and justify my methodological choices, and outline how they were influenced by this perspective.

4.3   Philosophical perspective

As noted above, identifying the philosophical perspective of the researcher helps to clarify why and how particular methods have been used. It also reveals the assumptions that the researcher is making about the nature of the data they have collected and the interpretations that they have made of it.   In particular, identifying the researcher's perspective makes clear their beliefs about whether they consider it possible to obtain 'the truth' or 'a truth' about a particular question, and what steps they consider are necessary or possible in order to demonstrate or claim that this answer is 'true'. This is particularly significant within qualitative research, where a particular research design or method may be informed by one of several different philosophical positions, with consequently differing understandings of the value and status of the data which is collected (Williams and May, 1996, Seale, 1999b). As Hughes notes:

> *"Every research tool or procedure is inextricably embedded in commitments to particular versions of the world and to knowing that world. To use a questionnaire… to take the role of participant observer,…and so on, is to be involved in conceptions of the world that allow these instruments to be used for the purposes conceived". (1990, p11)*

An interview can, for instance, be considered to create subjective information regarding people's experiences which is purely a product of that particular interaction, to produce information that points to a reality beyond that interaction, or may not be considered to generate valid data at all (Miller and Glassner, 2004). This lack of consensus regarding what constitutes a valid approach to answering a question, and the meaning of the answer obtained, necessitates clarifying the researcher's theoretical position. In the next section I therefore identify the major influences on my own ontological and epistemological perspective. In particular, I identify critical realism as offering a position consistent with my understanding of the nature of reality and how and what can be known about it, and explore the influence of feminist research thinking on my approach.

4.3.1   Critical realism

Critical realism was developed by Bhaskar (1978), and is also sometimes referred to as 'transcendental realism' (Hughes and Sharrock, 1997).   It encompasses both ontological and epistemological considerations. In some ways, critical realism forms a bridge between the 'poles' of constructivism and positivism (Ritchie and Lewis, 2003, Braun and Clarke,

2006), combining ontological realism with epistemological relativism (Hughes and Sharrock, 1997, Danermark et al., 2002). These two aspects will now be explored, with reference to how they impact on the research.

4.3.1.1 Ontological realism

Ontology is concerned with the nature of reality, and in particular whether there is an objective reality which exists independently of any ability that we have to study it; whether there is a shared reality or many different realities experienced by individuals (Ritchie and Lewis, 2003). Within the natural sciences, there is a broad consensus that an objective reality does exist – a position defined as realism (Ritchie and Lewis, 2003). There is however no such agreement within the social sciences, where healthcare can be located. Many in these disciplines hold a relativist position which considers that there is no objective reality i.e. that social phenomena do not exist outside the human mind and its interpretations of those phenomena (Collier, 1994, Ritchie and Lewis, 2003). This distinction is important in the implications it has for the purposes of research: a realist will have an intention of trying to discover, describe and understand reality – or at least move towards this goal even if it is never fully achievable. A relativist contends instead that as multiple realities exist, the purpose of research is not to identify the 'true reality' amongst a range of competing claims but to explore and represent this diversity.

Critical realism, as its name implies, holds a realist ontological position - that there are real things which exist independently of our experience of them (Collier, 1994) and it is therefore possible through research to try to *"capture the intrinsic nature of the thing"* (Hughes and Sharrock, 1997, p168). The implications of this perspective are that all knowledge is not equally fallible and all beliefs and descriptions are not considered equally valid (Collier, 1994, Danermark et al., 2002). It is instead possible to make judgements between different theories about their ability to explain the mechanisms underlying a particular phenomenon, with the goal of deepening knowledge of it (Collier, 1994, Danermark et al., 2002). This position can be summed up in Bhaskar's assertion that *"changing knowledge of unchanging objects is possible"* (quoted in (Collier, 1994, p88)), the aim of research being to seek this knowledge. However, as Bhaskar's words indicate, knowledge *does* change, and it is therefore never possible to claim a final, infallible understanding and explanation of a phenomenon (Collier, 1994). Knowledge is seen as always being filtered through the lens of a subjective observer, giving critical realism a position of epistemological relativism, which will now be considered further.

4.3.1.2 Epistemological relativism

Epistemology concerns the ways we can know about reality and what the basis of our knowledge is, including whether some types of knowledge – such as scientific knowledge - can be considered 'better' or more reliable than others (Hughes and Sharrock, 1997). Ritchie and Lewis (2003) identify two key epistemological stances of positivism and interpretivism, which offer different understandings about how the social world can be studied, and the impact of the researcher on the data they gather. A positivist perspective assumes not only that there is an objective reality i.e. a realist ontology, but also that it is possible to know that reality in an objective way, and that the influence of the researcher can be eliminated. From this perspective, it is possible to study phenomena in the natural

and social sciences using the same methods, which are those of the natural sciences, and human behaviour can be explained and therefore predicted in the same way as other aspects of the natural world (Ritchie and Lewis, 2003).

In contrast, an interpretivist perspective, which is where critical realism is located, challenges these basic assumptions, asserting that although an objective reality may exist, knowledge of it is always mediated by our subjective experiences. From this epistemologically relativist perspective, people's beliefs and understandings of their experiences are not entirely consistent and stable, but may change over time and are shaped by their interaction with their social, political, economic and cultural context (Collier, 1994, Hughes and Sharrock, 1997). This subjectivity influences both research participants and the researcher, neither of whom can step outside their own experience and describe 'reality' in an objective way. The researcher's own perspective will affect the interpretation of the data that they gather, which is in itself formed of other people's interpretations and understandings of their experiences. Knowledge is therefore always partial and fallible, and it is neither possible nor helpful to ignore the context in which that knowledge has been acquired (Danermark et al., 2002).

Critical realism asserts that social phenomena fundamentally differ from natural phenomena in a number of ways which directly affect how research is carried out (Hughes and Sharrock, 1997). Firstly, they differ in their nature. Social phenomena exist only within a particular social context, which gives them their meaning; in contrast, natural phenomena are naturally produced, although their meaning may be socially defined (Collier, 1994, Danermark et al., 2002). Secondly, social research is always undertaken within open systems; it is never possible to isolate the phenomenon being studied, and thus many external factors will always be influencing the outcomes of the research (Collier, 1994, Danermark et al., 2002). Additionally, the act of research changes the experience and behaviour of those being studied, which will in turn impact on the researcher – thus the researcher and the researched cannot be entirely separated (Danermark et al., 2002). This can be contrasted with a laboratory experiment where it is suggested (although not universally accepted) that a phenomenon can be studied in isolation, without being affected by any interaction with the researcher. These differences between social and natural phenomena impact on the nature of the knowledge that can be obtained about them (Collier, 1994). Knowledge of social phenomena can never be gained independently of the meanings and values of those studying it, and findings are always partial and provisional, meaning that explanations will be in terms of 'tendencies' rather than causal mechanisms, and accurate prediction is impossible (Collier, 1994, Danermark et al., 2002, Ritchie and Lewis, 2003).

Although knowledge of social phenomenon is always fallible, critical realism's realist ontology asserts that it is *variably* fallible; findings can therefore still be assessed as to whether they are *"more or less like the truth of this reality"* (Danermark et al., 2002, p25). One key way of assessing knowledge is by understanding how it has been produced: what methods have been used, and how decisions were made to select those methods (Collier, 1994).   The distinctive nature of social phenomena affect the methods of research that can be used to study them (Collier, 1994), and it is the *consistency* of these methodological

decisions with ontological and epistemological considerations which ensures that the knowledge produced is valid, reliable and relevant:

> *"Method, object and purpose must be considered simultaneously and in relation to each other, and must also inform all other choices…. including techniques of data collection and analysis." (Danermark et al., 2002, p27).*

The interpretivist position emphasises the importance of clarity regarding the context in which the research data has been collected, as this is essential to fully understanding the meanings and interpretations that research participants give to the phenomenon under study (Danermark et al., 2002). The researcher needs to provide relevant contextual information regarding participants, and ensure their own perspectives and experiences are made clear so that it is possible to consider how these have affected the research process and its findings, and the appropriateness of their methodological choices can be judged (Ritchie and Lewis, 2003). The next section identifies the ways in which I consider my critical realist position has informed this study's methodology and methods.

4.3.1.3 Impact of critical realism on the research

An individual's beliefs and values affect every decision and action, and it is clearly not possible to identify all these effects, but within the context of this research, the following decisions have particularly been influenced by a critical realist perspective:

- selection of a qualitative methodology for the research, and the use of an inductive approach, focusing on exploring the experiences and understandings of the research participants from their perspective;
- selection of the criteria used to assess the quality of the study, in particular emphasising transparency at all stages of the research process;
- consideration of how my familiarity with mindfulness and Buddhism affected data collection and analysis, including identifying how it may have improved the quality of the data by allowing a greater depth of exploration of the subject. This carries an assumption that there are 'better' data to be obtained, which more accurately depict the reality of individuals' experiences;
- recognition that at all stages of the research, the perspectives of those involved - participants, researcher, transcribers and supervisors – will have influenced the shaping of the data to varying degrees, but that these perspectives contributed towards deepening knowledge of the subject rather than each creating a <u>different</u> knowledge based on their own perspective;
- similarly, recognition that the different methods used each provided a particular perspective and helped to deepen and develop the understanding of the subject, but did not provide 'validation' of the data gathered at earlier stages (see 4.6.2);
- inclusion of a reflexivity section (Chapter 9) which elucidates some of the ways in which the interactive 'open system' between researcher, participants and the research topic has affected the process and outcomes of the research.

4.3.2 Feminist research

A feminist approach to research arose out of concerns around the power imbalance between men and women in society. In particular, it highlighted gendered ways of thinking, and how these impacted on the relative status of different types of knowledge and the conduct of research to create that knowledge (Rose, 1983). Feminist thinking, based on an epistemological relativism, recognised there were competing interpretations of social phenomena and that these interpretations affected what was viewed as 'true', i.e. what was considered to be 'reality' (Danermark et al., 2002). They further identified how certain interpretations of experience had a more powerful position within society, and thus had a bigger impact on defining the social, political and economic agenda (Olesen, 2000). These interpretations were largely those created through a scientific process dominated by men and by what could be termed 'male' thinking (Rose, 1983, Williams and May, 1996). Women's position of disadvantage was seen to be further reinforced by the fact that decisions were differentially made by men, who occupied more positions of power. Research was recognised to have both oppressive and emancipatory potential and, as part of a wider radicalising movement, feminists argued that it should be conducted in ways that challenged inequality and brought about change in society (Olesen, 2000, Ritchie and Lewis, 2003). Similar arguments were put forward by other disadvantaged groups.

Within the research context, feminists argued that the dominant ways of thinking privileged traditionally male concepts of rationality and objectivity (Rose, 1983), and viewed the world of emotion and bodily experience as subjective elements that needed to be overcome and controlled within the research process (Oakley, 1981). As this world was one with which women were more familiar, their knowledge and ways of knowing were largely excluded (Oakley, 1981, Olesen, 2000). This not only disadvantaged women, but was seen to produce a partial and inferior knowledge of the world which was not grounded in everyday human experience (Rose, 1983, Williams and May, 1996). Feminist researchers argued that research methods needed to be able to capture the world of feeling and emotion. This, together with a vision of research as an emancipatory tool, led to new ideas about how research, and interviews in particular, should be conducted (Oakley, 1981, Wolf, 1996) . These ideas will now be explored, as although I do not consider this study to be feminist research, its values have influenced its conduct.

4.3.2.1 Impact of feminism on the research

Valuing emotion and feeling

Feminist research privileged subjective dimensions of knowing, i.e. those concerned with emotion and bodily experience, seeing this as necessary to counterbalance the dominance of rational, 'objective' approaches. Whilst this approach focused on women's experience, the principle of valuing subjectivity can be extended to all participants' experience, including the researcher. This perspective echoes the interpretivist emphasis on understanding the context in which data are collected, and its recognition of the need to consider all aspects of a participant's experience in order to understand it. At least partly due the influence of feminist thinking over the last few decades (Olesen, 2000), qualitative research generally has a strong emphasis on subjective aspects of experience, and these ideas are therefore firmly embedded within my research.

Disclosure in the interview relationship

Feminist researchers argued that the traditional research process, in particular the research interview, often mirrored and reinforced existing power imbalances (Wolf, 1996) . This was particularly evident when the research concerned a disadvantaged group, such as women. The researcher, often in a relatively privileged socio-economic position compared to those they were interviewing, was seen to be acting as a *"depersonalised extractor of data"* (Ritchie and Lewis, 2003, p160). They defined the agenda of the research, determining the questions that were asked, and revealing little or no information about themselves in order to reduce their own impact on the research (Oakley, 1981). These factors acted to reinforce the hierarchical and unequal aspects of the relationship, and feminists argued that this was unethical and politically unacceptable (Wolf, 1996). Additionally, it was suggested the data produced were of limited value, participants being unlikely to reveal sensitive information, particularly concerning their experience of disadvantage, in such a context (Oakley, 1981).

An alternative approach to interviewing women was proposed, which aimed to reduce the hierarchical nature of the relationship by minimising the distance between researcher and researched. This was to be achieved in two ways. Firstly it was argued that women should interview other women. This was based on an assumption of a shared experience of disadvantage within society which would enable greater understanding and insight, and reduce inequalities in the interview setting (Oakley, 1981, Wolf, 1996). Secondly, the importance of researcher disclosure was emphasised, such as the researcher sharing something of their own life experiences and also allowing their own emotional reaction to the participant's story to be apparent (Wolf, 1996). A changed balance of control was inherent in this approach, the researcher being willing to respond to the participant by answering their questions and allowing the direction of the interview to be influenced by their concerns. Through this process, research participants were seen as gaining a more equal and reciprocal relationship and an active role in the research process, leading to a greater sense of empowerment (Wolf, 1996, Olesen, 2000).

My research was not designed with an explicitly feminist agenda, which would have required a specific focus on women's experience of mindfulness and long term illness. Therefore the goal of same gender interview relationships was not appropriate, and also one that has been questioned and certainly potentially oversimplifies a complex set of power relationships (Wolf, 1996, Olesen, 2000). However, the issue of disclosure was one to which I gave some consideration. I was aware that people with LTCs are often in a disempowered position for economic and social reasons, which can impact on individuals' sense of worth and identity, and I did not want the research to contribute to this. Furthermore, the use of repeated interviews allowed relationships to be established, creating more potential for disclosure (Oakley, 1981). As the research progressed, decisions regarding disclosure of my own health problems also became an issue I had to address. My decisions and reflections around disclosure are discussed in 9.2.3.

Ensuring participant benefit

Feminist concerns around the potentially negative effects of research participation reflected a much broader movement towards exploring the emancipatory potential of

research and developing new approaches in which participants could actively engage with and benefit from their involvement, both individually and as a group (Fontana and Frey, 1998). This concern was also reflected in the interview context, with feminist researchers addressing not only issues of personal disclosure but also the sharing of information with participants (Oakley, 1981). It was argued that it was unethical, as well as against the goal of reducing distance, to withhold potentially helpful information in the interests of maintaining neutrality and minimising the researcher's impact. Researchers were seen to bring potentially valuable knowledge and experience to the interview, and to have a responsibility to appropriately make this available, particularly in response to direct questions (Oakley, 1981).

Within this study, whilst recognising that participating in research is often beneficial in its own right (Clark, 2010), the principle of participant benefit guided me on occasions to prioritise ensuring the process was as beneficial as possible over maintaining a 'neutral researcher' role. This is discussed further in the reflexivity section 9.2.4.

4.4   Selecting a qualitative methodology

The previous section has identified critical realism and feminism as key perspectives which have influenced my thinking and action in relation to this research. Both philosophies hold an interpretivist epistemology, which recognises the subjectivity inherent in the research process. This was significant in informing my decision to select a qualitative methodology, which will now be explored.

4.4.1 The value of a qualitative approach

Qualitative research is variously defined, but is generally characterised as focusing on words rather than numbers, and on exploring meaning and interpretation rather than the measurement and relationships of variables (Ritchie and Lewis, 2003, Corbin and Strauss, 2008, Creswell, 2009). It is concerned with creating an in-depth description and understanding of a particular phenomenon or situation, using methods that involve collecting detailed information from a relatively small sample of participants through close interaction with them (Ritchie and Lewis, 2003, Corbin and Strauss, 2008).

In contrast to the creation and manipulation of the environment in the experimental design of quantitative research, qualitative strategies adopt a naturalistic approach, aiming to study people's experiences in their natural setting. This enables, for example, a greater exploration of how people integrate interventions into their daily lives rather than exploring their responses in the more artificial context of controlled trials (Verhoef et al., 2002). Most qualitative research has an interpretivist basis, privileging people's own description and explanation of their experiences, and seeking to understand the subjective meanings they attach to them (Lincoln and Guba, 1985, Snape and Spencer, 2003, Pope and Mays, 2006). It is also therefore a predominantly inductive methodology, focusing on identifying patterns and generating concepts from the data rather than seeking to confirm or refute a predetermined hypothesis (Ritchie and Lewis, 2003).

A qualitative approach can provide a depth of insight and understanding into existing quantitative data (Pope and Mays, 2006). It has an explanatory function, enabling the researcher to ask 'why' and 'how' questions about those data, and explore the complexity of the experiences that give rise to them. It is also an approach suited to understanding how experiences change and develop over time (Ritchie and Lewis, 2003). Through such exploration, qualitative research can contribute to understanding the mechanisms and processes at work in a situation, and is therefore often used where theory is not well developed (Pope and Mays, 2006, Blignault and Ritchie, 2009).

Finally, qualitative research has a particular role in understanding the effects of complex interventions, including complementary and alternative medicine. Verhoef et al (2002) note that such interventions often consist of many elements, have holistic rather than condition-specific goals, and are often individualised in their approach. In such circumstances, patients' responses are likely to also be complex, individual and not fully captured by standard outcome measures. Qualitative approaches enable these subtle and perhaps unanticipated effects to be more fully explored, and for the variation in experience between individuals to be understood (Verhoef et al., 2002).

As identified in Chapter 3, although there is a growing body of mindfulness research, there are still significant ways in which the complexity of people's experience of mindfulness and its mechanisms of action are not fully understood. This research addressed one of those areas, seeking to gain an in-depth understanding of people's long-term experiences of practising mindfulness in the context of living with a LTC. In particular it explored if, why and how people integrated mindfulness practice into their everyday lives, and what effects this had on their behaviour and thinking in relation to their condition. It also sought to identify variation in people's experiences, and to explore factors that may contribute to this variation. Such questions called for a qualitative approach, with its focus on identifying and privileging participants' *own* descriptions and understandings of their experience, and then inductively developing theory from interpretation of this data. Existing understandings of mindfulness and living with chronic illness were thus explored at a later stage rather than defining the research question and direction of investigation.

MMBIs are complex interventions which have a variety of subtle and sometimes profound effects on individuals' experiences, some of which are not readily identifiable through quantitative means. A qualitative approach provides an opportunity to explore the depth and breadth of these experiences more effectively and to identify changes which might otherwise be missed. The potentially sensitive nature of the research topic was another important consideration. Living with a LTC can be challenging and distressing, and to explore this experience in depth necessitates a responsive and flexible approach to avoid unnecessary harm to participants, a key ethical principle. Qualitative research approaches are particularly valuable in such settings, offering a process which can be adapted to the needs of the situation, particularly with regard to the detail and sequence of questions being asked (Ritchie and Lewis, 2003).

4.4.2 Selection of a grounded theory approach

On the basis of the considerations above, a purely qualitative methodology was selected for this study. Qualitative research does not however constitute a unified methodology,

and a range of possible strategies exist, which inform how data collection, analysis and reporting are carried out. The approach selected depends on the nature of the research question, and the kind of answers it is hoped to obtain (Creswell, 2009).   Two methods, phenomenology and grounded theory (GT), were considered as possible approaches for this study, both offering a means to gain an in-depth understanding of and insight into people's experiences.   The key characteristics of these two approaches will now be explored, and the reasons for selection of GT identified.

4.4.2.1   Phenomenology

As with other methods, phenomenology contains a diversity of positions, but its key focus is on exploring participants' experiences of a phenomenon to identify the 'essence' of that experience as perceived by those participants (Danermark et al., 2002, Creswell, 2009). This is usually undertaken through a small number of in-depth, unstructured interviews in order to understand participants' 'lived experience' of a particular phenomenon and its meaning to them (Creswell, 2007).   Research questions using a phenomenological approach are generally broad, allowing for an open exploration whose direction is not predetermined by existing theories (Richards, 2007, Creswell, 2009). The intention is to seek an understanding of participants' experience *as a whole*, rather than trying to identify its component parts or develop a theory as to how and why the experience has arisen (Richards, 2007). This is achieved through coding and categorising the data in order to identify themes within it and through repeatedly reviewing and reflecting on the findings to explore as many dimensions of the experience as possible.

Phenomenology is an interpretivist approach, recognising the importance of context to any meaningful understanding of social situations and is concerned with participants' perceptions of their experience rather than an objective understanding of it. As part of this, the researcher's own subjectivity is acknowledged, but within this approach, it is generally considered important to try to set this aside and describe the phenomenon objectively or with as little bias as possible. This is done through a process of 'bracketing', where the researcher's assumptions are identified in order to avoid them impacting on the research process (Creswell, 2007, Richards, 2007).

In relation to this study, phenomenology offered the potential of enabling a detailed understanding of participants' experiences of practising mindfulness in the context of living with chronic illness. It did not however provide such an effective means to understand the processes by which these experiences had come about i.e. what changes had given rise to it and why this was the case. Thus, although a phenomenological approach would have provided an in-depth *description* of the role of mindfulness in living with a LTC, it would not allow for any *explanation* of this.   In addition, I did not feel comfortable with the concept of 'bracketing', considering it more realistic and helpful to work reflexively and aim to identify how my experience affected the research process. Finally, on a pragmatic level, the complex philosophical position in which phenomenology is embedded was one which was unfamiliar and challenging to me. This, together with the lack of clarity about how the method should be applied in practice, led me to consider this not to be the most suitable approach for someone new to qualitative research. For these reasons, I decided not to use phenomenology for this study.

4.4.2.2 Grounded theory

Whilst GT shares similarities with phenomenology, including its focus on participants' interpretations of their experience, there are a number of key differences. In particular, GT focuses on exploring the *process* taking place in a situation, i.e. what people are experiencing and how they explain what is going on (Creswell, 2009). It aims not only to provide a detailed, rich description of a phenomenon, but to develop theory to identify how and why this may have come about (Creswell, 2007, Birks and Mills, 2011). This dynamic approach is therefore particularly valuable in situations which are not well understood, where existing theories do not adequately explain a phenomenon. Like phenomenology, GT's methods enable a systematic exploration of people's experiences through a series of stages of data collection and analysis. Distinctively however, it uses *concurrent* data collection and analysis which allows insights gained during earlier stages of data collection to inform the direction of its later stages, particularly in terms of sampling strategies and interview questions. By enabling ideas that could not be anticipated at the start of the study to be pursued, theory can thus be developed more effectively.

When considering the purpose of this study, GT appeared to offer a suitable approach. Its focus on developing a greater understanding of process was well suited to exploring if and how mindfulness had influenced people's experiences of their LTC over time. As identified previously, the mechanisms of mindfulness are still not fully understood, so GT's capacity to enable theory development was an important consideration. Additionally, its structured approach was one that offered me, as a relatively inexperienced qualitative researcher, sufficient guidance to use effectively. In the next section GT will be explored in more depth, identifying its diverse strands which, whilst not fundamentally changing the *focus* of the approach, impact on aspects of how it is used (Birks and Mills, 2011). In order to clarify my own use of GT, I will discuss this diversity and identify my own position within it, but will start by outlining some characteristic features of the method as a whole.

4.4.3 Exploration of grounded theory

4.4.3.1 Key features of grounded theory

GT was developed as a new approach to qualitative research by Glaser and Strauss, whose seminal book, *The Discovery of Grounded Theory* (Glaser and Strauss, 1967), presents its key features and techniques. GT was developed to address a prevailing view that qualitative research lacked rigour, and from a concern that theory was often being developed without a sound connection to empirical data (Glaser and Strauss, 1967). It provided a systematic process which, in contrast to strategies based on theory-*testing*, was 'grounded' in empirical data and could be used to inductively *generate* theory from it. Although there have been significant developments in GT since that time, there remain a core set of characteristic methods, some of which are given greater significance in particular GT approaches (Birks and Mills, 2011). These can be identified as follows:

- A *coding process involving a number of stages*, during which the codes develop from being close to the original data to becoming categories which are used to identify more abstract and conceptual ideas within it (Glaser and Strauss, 1967, Strauss and Corbin, 1998, Charmaz, 2006). Different GT approaches outline

varying levels and degrees of complexity in the stages of coding, but all emphasise a progression towards a more theoretical perspective on the data which is characteristic of the inductive process (Strauss and Corbin, 1998, Charmaz, 2006). In many approaches, the final stage of this process is the development of a core or central category, which links all the other categories and encapsulates the main theme identified within the analysis (Corbin and Strauss, 2008);

- *Concurrent data collection and analysis*, whereby early findings are analysed to generate ideas which are then tested through the later stages of data collection. This leads into:

- *Theoretical sampling*, in which particular directions of recruitment or questioning are developed during the research in order to explore the developing theory (Glaser and Strauss, 1967, Strauss and Corbin, 1998, Charmaz, 2006);

- *Constant comparison of data*, in which incidents, codes and categories are compared as part of a process of creating an integrated and grounded theory which takes account of all the different themes identified within the data;

- *Memo writing* as a key tool for recording and developing the researcher's thinking. This includes reflections on coding and potential directions for theoretical sampling, and explorations of the researcher's own experience and how it is influencing the direction of the study (Charmaz, 2006, Corbin and Strauss, 2008, Birks and Mills, 2011) . This leads onto:

- *Theoretical sensitivity*, which acknowledges that the researcher's own experience and knowledge influences the way they will understand and interpret the data they collect (Glaser and Strauss, 1967, Charmaz, 2006, Corbin and Strauss, 2008). There are considerable differences within GT about how theoretical sensitivity should be managed within a study;

- *Creation of a grounded theory* which has been built from empirical data and which comprehensively "explains a process or scheme associated with a phenomenon." (Birks and Mills, 2011, p12). This is the ultimate goal of the GT process.

Although these methods characterise GT research in general, there are a number of versions of GT which have developed since Glaser and Strauss's original work. These developments have arisen from both different understandings of how GT should be applied, and the influence of newer philosophical perspectives such as constructivism and postmodernism (Birks and Mills, 2011), which have significantly impacted on social research as a whole.

4.4.3.2   Divergent strands and locating myself within them

The first significant divergence within GT was between Glaser and Strauss themselves, who took the method in somewhat different directions. This resulted in Glaser criticising aspects of Strauss's key work with Corbin, *Basics of Qualitative Research* (1990). In particular, Glaser considered that Strauss and Corbin's more structured approach to coding risked imposing too many predetermined concepts on the data, thus 'forcing' it into a particular shape, rather than letting the data 'speak for itself' (Glaser, 1992).

Glaser also maintained a very clear position in relation to theoretical sensitivity, suggesting that no prior reading of related literature should be done as this also would create a

particular lens through which the researcher would view the data. Whilst agreeing that existing theory needs to be tested for its 'fit' with the data rather than the other way round, other writers have taken a more flexible approach to this issue (Charmaz, 2006, Corbin and Strauss, 2008). Charmaz pragmatically notes that projects often require at least some familiarity with the literature in order to obtain funding or approval for the research. This was a salient point for this study, as a review of the literature was an essential element of the PhD 'upgrade' process, providing evidence of the potential value of the research and the rationale for the development of the research question.

Although caution is needed in making retrospective interpretations, Glaser and Strauss's original thinking was certainly strongly influenced by the post-positivist era in which they were writing, which assumed an objective reality that could be discovered by an objective observer (Charmaz, 2003, Birks and Mills, 2011). Their methods acknowledged the influence of the researcher's perspective, but they – and Glaser in particular - considered it possible to transcend this to a significant extent, if not completely. Glaser's concern to avoid any researcher influence on the categories which 'emerge' from the data suggests an underlying ontological realism and epistemological positivism, although Glaser has never explicitly identified himself in this way. Others have associated him with critical realism, but my understanding of this philosophical position is that its interpretivist epistemology emphasises the influence of perception on experience and how objective 'reality' can therefore never be known. For these reasons, I considered Glaser's approach to be incompatible with my own position.

Similar uncertainties exist around Strauss and Corbin's philosophical position, which they never explicitly identify, although constructivist writers such as Charmaz (2006) describe them as post-positivists. This categorisation has become less clear however, as in her more recent writing, Corbin acknowledges the impact of newer philosophical and political perspectives on her thinking:

> *"I agree with the constructivist viewpoint that concepts and theories are constructed by researchers out of stories that are constructed by research participants [….] Out of these multiple constructions, analysts construct something they call knowledge." (Corbin and Strauss, 2008, p10)*

This understanding has brought her much closer to the work of Charmaz, but there remains a different emphasis on the influence of the researcher's perspective and values. Whilst Corbin acknowledges that this affects what is seen and what interpretation is made, it has a more pivotal role in constructivist thinking. Thus, Corbin recommends that reflexivity is dealt with by including a statement about the researcher's position (Corbin and Strauss, 2008), whilst Charmaz emphasises that these values affect all aspects of the research process (Charmaz, 2004, Charmaz, 2006).

One important contribution to GT of Strauss and Corbin's work was to turn its ideas and principles into a clearly structured set of methods which could be followed by other researchers (Strauss and Corbin, 1998). In particular, they developed a system of coding which consisted of a number of stages – open, axial, and selective coding – through which increasingly theoretical and conceptual understandings of the data could emerge. To facilitate this, they also introduced tools such as the *"conditional/consequential matrix"*

(Strauss and Corbin, 1998, p181) to identify particular properties of the data. Although they acknowledge that these tools can be used flexibly, this area of their work has provoked significant discussion and dispute. Glaser considered such a prescribed structure moved away from the empirical basis of GT, imposing categories that were not inherently present in the data. Similar concerns have been expressed by later writers who suggest that their use *"may limit what and how researchers learn about their studied worlds and, thus, restrict the codes they construct."* (Charmaz, 2006, p62). Charmaz proposes a more flexible approach, which draws on such models *only* if they relate to the emerging themes in the data, rather than starting out with an intention to populate them as the analysis progresses (Charmaz, 2006). Through her two-phase model of open and focused or selective coding, Charmaz still recognises the need to move towards a more conceptual rendering of the data, but uses a simpler framework within which other tools may be employed, as required, to progress the analysis.

Perhaps reflecting the philosophical shift identified above, it is notable that in her more recent work, Corbin appears to have moved to a coding approach which is more similar to Charmaz (Corbin and Strauss, 2008). In particular she no longer presents axial coding as a separate stage, and emphasises that methods should be used flexibly in order to meet the goals of the research and the needs of the researcher. Both writers also recognise that it is not necessary to adopt their particular theoretical stance to use the methods outlined in their books (Charmaz, 2006, Corbin and Strauss, 2008). In particular, Charmaz notes that *"constructivist grounded theory can also serve researchers from other traditions."* (Charmaz, 2006, p184). She lists a range of interpretivist epistemologies, including critical realism and feminism, which she sees it as compatible with.

Having explored these different ideas and approaches, I found that Strauss and Corbin's coding approach added an unhelpful layer of complexity and conceptualisation, and also shared Glaser and Charmaz's concerns that imposing a predefined structure moved away from a data-driven, inductive process. Although their work was valuable in developing my understanding of the GT, I therefore did not adopt Strauss and Corbin's coding structure and instead based my approach on Charmaz's simpler, two-phase model. I also adopted an approach to reflexivity which is closer to Charmaz's, acknowledging how the researcher creates a subjective interpretation of the data and therefore trying to make transparent my own interactions with the research process (Charmaz, 2006). However, from my critical realist perspective, I do not share Charmaz's constructivist understanding that nothing exists beyond the interpretation and interaction, as I retain a belief that there is a reality I am attempting to shed some light on, however partial and filtered that may be.

4.5   Ethical considerations

An ethical approach to all aspects of research is of fundamental importance, particularly when research involves living beings, where the potential for harm is greater than in more theoretical work. As discussed in the previous section, the position of researcher is a powerful one, and therefore carries considerable responsibility to ensure, as far as possible, the safety and wellbeing of the research participants (Creswell, 2009). This is particularly true in qualitative research, where there is close engagement with participants,

who are often sharing highly personal information and where there is more potential for unanticipated situations arising (Ritchie and Lewis, 2003), including disclosure of harm.

A considerable amount of guidance regarding ethical issues is available (NRES, 2009, NPSA, 2011), and this has informed many aspects of the research design including ensuring appropriate procedures were developed to address informed consent, confidentiality, facilitating participation, data protection and protection from harm (Ritchie and Lewis, 2003). The way these principles were applied is discussed in 5.5. Ethics extends beyond formal procedures however, and is also concerned with how those procedures are applied, particularly how the researcher engages with the participants within the research setting (Hallowell et al., 2005). Ethical principles inform such decisions, but cannot determine the course of action taken, as the researcher's interpretation of those principles will also affect their response to issues arising in the situation. As noted in 4.3.2.1, this includes the interaction between myself and other research participants, which are explored in 9.2.

4.6   Quality and credibility

The terms 'quality' and 'credibility' are used with a variety of meanings in qualitative research, so it is important to clarify the interpretation being used here. Seale notes that quality is a multifaceted concept, and identifies two aspects: an *"external dialogue"* and an *"internal dialogue"* (Seale, 1999a, p410). The 'external dialogue' concerns the impact of the research in the external environment, including its relevance and importance, whilst the 'internal dialogue' explores the 'internal logic' of the work and how well the claims being made are supported by evidence. This latter aspect is variously termed validity, credibility, rigour or trustworthiness. I have chosen to use the term 'credibility', sharing Corbin's (Corbin and Strauss, 2008) and Lincoln and Guba's (1985) preference for it over 'validity', a term which carries associations with positivist and quantitative approaches and therefore not consistent with my interpretivist epistemology. Lincoln and Guba describe credibility as concerned with the *"truth value"* of research, summarised by Beck as being a measure of *"how vivid and faithful the description of the phenomenon is"* (1993, p264).

4.6.1   Selection of criteria for evaluating quality and credibility

A range of frameworks have been developed for evaluating quality in qualitative research, with widely differing opinions regarding the most appropriate criteria and approach to use (Cohen and Crabtree, 2008) . These differences largely focus around the 'internal dialogue', i.e. credibility, and reflect differing ontological and epistemological positions. I explored a range of options, considering their fit with my own critical realist perspective, which was not explicitly identified as the basis for any of the criteria explored. A number of frameworks provided helpful guidance, and I found Meyrick's (2006) work particularly useful. She suggests two key criteria to establish credibility:

- Transparency – "disclosure of all relevant research processes";
- Systematicity – *"the use of regular or set data collection and analysis process, any deviations in which are described and justified"* (Meyrick, 2006, p803).

These principles echo Corbin's suggestion that findings will only be credible and applicable if the research has been carried out in a rigorous way (Corbin and Strauss, 2008), which can be established if they are presented in a way that is open to scrutiny.

In addition to Meyrick's work, I have drawn on Charmaz's criteria (2006) to ensure that wider, more 'external' aspects of quality are considered. Her work focuses on GT, and is thus particularly relevant to this study. As noted above, Charmaz also considers her approach compatible with a range of perspectives including critical realism (Charmaz, 2006). Her framework offers a comprehensive overview of quality, with four key criteria: credibility, originality, resonance and usefulness. Charmaz's credibility criterion is largely similar to Meyrick's work, focusing on the research's internal consistency; the other three criteria address how it engages with a wider context and audience. I have predominantly drawn on Meyrick to evaluate credibility, as I found her approach clearer and more practically useful. However, as Meyrick does not consider the wider aspects of quality, I have drawn on Charmaz to explore questions of originality, resonance and usefulness. The application of these criteria to this study is discussed in 10.3.2.

4.6.2 Triangulation

One particular aspect of credibility which is open to very differing interpretations is triangulation. This concerns how different sources of data and methods of data collection are understood to relate to each other within a study (Sandelowski, 1995). From a positivist perspective, with its assumption of *"a single fixed reality that can be known objectively"* (Seale, 1999b, p53), triangulation is understood as the use of multiple methods or repeated experimentation to validate the research findings (Bloor et al., 2002). As discussed in 4.4.1 however, qualitative research is predominantly based on an interpretivist perspective (Lincoln and Guba, 1985). Within this paradigm, different research methods and researchers inevitably produce different data due to the subjectivities inherent in the process. As a result, direct comparison of findings from different sources is not possible, and data collected using one method cannot validate or invalidate that from another (Sandelowski, 1995). In this context, triangulation has a different value. It does not offer completeness or final confirmation of knowledge, but *"may serve to deepen and enrich a researcher's understanding of a topic."* (Bloor et al., 2002, p13), and increase their insights into its complexity. In the light of this, Richardson proposes 'crystallisation' rather than triangulation as a more appropriate analogy to represent the relationship between different methods and data sources (Richardson, 2003). She suggests that the crystal, with its many facets creating their own patterns, and which may be viewed from different angles, more accurately reflects the provisional and partial nature of the knowledge gained through the research process. Within this study, my use of interviews, diaries and focus groups is based on this latter understanding of triangulation, where each method provides additional insight into the research question and enhances the credibility of the findings, but does not make it possible to obtain or confirm a final and objective truth.

4.6.3 Researcher's position

My interpretivist epistemological position means I believe that the researcher both affects and is affected by the research process. Their perspective and prior experience will

influence how the research is designed and carried out, and how the findings are interpreted (Snape and Spencer, 2003, Ritchie and Lewis, 2003, Creswell, 2009). The researcher's subjectivity cannot be removed and, as Seale (1999b) notes, attempts to do so would be detrimental, removing contextual detail from the research which adds to the value and transferability of its findings. It is instead important to apply Meyrick's (2006) criterion of transparency, and make the researcher's position as explicit as possible, so that judgements can be made – by both the researcher and others - about how this may have impacted on the research process and findings. This is addressed through reflections on the analysis process at the end of Chapter 5 and a reflexive account in Chapter 9.

4.7   Chapter summary

This chapter has reviewed the various methodological and philosophical considerations which have influenced how this research has been designed and conducted. The philosophies of critical realism and feminism have been identified as key influences on the design and conduct of the research, including the selection of a qualitative approach. The reasons for selection of grounded theory as the guiding methodology for the research, and in particular an approach informed by Charmaz's work, have been explored and identified. Ethical and quality issues have also been considered. The next chapter presents the methods used within the study, and how their use has been informed by these considerations.

Chapter 5
Methods

5.1 Introduction and chapter overview

The thesis research question and subsidiary questions were identified in 3.4 as:

How does practising mindfulness affect people's experiences of living with a LTC?

- How do people understand and describe their experiences (positive and negative) of practising mindfulness as taught through Breathworks in relation to living with a LTC?
- In what ways and for what reasons do people with LTCs integrate mindfulness into their lives?
- How do people with LTCs perceive that practising mindfulness affects the way they relate to and manage their condition?
- In what ways are people's experiences similar, and how do they differ?
- Does the variation seem to relate to any identifiable characteristics e.g. condition, amount (e.g. frequency, length) of mindfulness practice, personal circumstances?

The previous chapter explored methodological and philosophical considerations, and identified how these informed decisions about how to address the research question. This chapter discusses how these understandings influenced the selection of the methods of recruitment, data collection and analysis, and provides a comprehensive account of how these methods were used in the study.

As discussed in 4.4.3, this study uses grounded theory (GT), and in particular draws on the work of Charmaz (2006) to guide the process of data collection and analysis. Informed by this approach, a phased recruitment and data collection process was employed, which involved the use of two-stage in-depth interviews, diaries and focus groups. Participants had all attended and/or delivered a course teaching mindfulness meditation and skills to people with LTCs. Data collection took place over approximately one year between June 2011 and July 2012, and involved 27 participants in 47 interviews, and 14 participants in two focus groups. Data were analysed as the interviews progressed, with findings informing the sampling strategy and subsequent interview and focus group questions. Analysis was based on Charmaz's (2006) model of open and selective coding. Memos were used throughout the process to facilitate reflection on and development of themes from the data. The research question was regularly returned to in order to maintain a clear focus, which became particularly important as the volume and complexity of data increased. Ethical principles informed all aspects of the research.

5.2   Recruitment

5.2.1   Study setting

In order to recruit participants with experience of mindfulness and living with a LTC, a decision was made to approach Breathworks, a national organisation specifically focused on teaching mindfulness skills to manage pain, illness and stress. Breathworks was established in 2001 by Vidyamala Burch, based on her own experiences of managing chronic pain (Burch, 2008). Initially focused specifically on pain management, the *"Living Well with Pain and Illness"* course (Breathworks, 2009b) has been widened in scope to include people with a wide range of physical and mental health conditions. The majority of participants still primarily have physical health problems, although many suffer with associated mental health conditions such as depression and anxiety. Some participants however do attend solely with mental health problems, and groups may contain people with a diverse range of conditions.

'Living Well with Pain and Illness' is an eight week programme, each weekly session lasting 2-3 hours plus an additional follow-on day or half day session. The course is based on MBSR (Kabat-Zinn, 1990), including a similar structure and emphasis on meditation (see 2.3.4), including regular home practice. It also incorporates activities from MBCT (Segal et al., 2002), including the 'three minute breathing space'. It has a number of distinctive features, in particular a more central focus on kindness towards self and others, which is demonstrated through the trainers' attitudes and taught through a 'kindly awareness meditation' and other activities. There is also a strong emphasis on mindfulness of daily activities, which is explored through a 'pacing diary' (Breathworks, 2009b). Breathworks delivers this and other related courses at approximately 20 locations across the UK, and in other locations in Europe, and 'Living Well with Pain and Illness' has more recently been made available in an online and distance learning formats.

The course has a standardised format, with printed materials and guided meditation CDs which are distributed to all participants. Trainers are required to have practised mindfulness for at least one year prior to teaching, and to attend a standardised trainer training programme. Trainee trainers observe and support courses before training with experienced trainers. Many trainers began as course participants, having benefited from finding mindfulness helping in managing their own LTC, although this is not a requirement.

Breathworks has closer associations with Buddhism than MBSR and MBCT; the founders and many of the trainers belong to the Triratna Buddhist Community (TBC), and courses are often delivered from TBC centres in the UK. Some of the course meditations are closely based on TBC practices, particularly the breathing and kindly awareness meditations. The courses are however explicitly secular, with no expectations made of religious belief or practice.

Breathworks has a strong commitment to on-going support for former students, known as 'graduates'. The organisation provides a range of local practice days, support groups and a national annual retreat. Graduates are also invited to maintain informal contact with the

trainers for advice and support. Due to overlap with TBC meditations, graduates are also informed of Buddhist events held at TBC centres, including regular meditation sessions.

The Breathworks *"Living Well with Pain and Illness"* course was selected for this research for a number of reasons, both pragmatic and theoretical:

- It is specifically aimed at people living with LTCs, and is delivered to heterogeneous groups, enabling exploration of the impact of mindfulness across a range of physical and/or mental health conditions.
- It has been offered both on a fee-paying basis and, less often, on a funded basis, including within the NHS, thus increasing the diversity of participants, including socio-economic status and health conditions.
- The standardisation of the materials and training delivery provides for some consistency in the intervention.
- As trainers are experienced mindfulness practitioners, many living with LTCs, they offer another, potentially more 'informed' perspective on their experience, as well as observations on a large number of other course participants.
- The course had been delivered at three locations within easy travelling distance for the research with other, more distant, locations available if additional recruitment became necessary.

5.2.2 Population

5.2.2.1 Sampling frame

The study population was drawn from three groups:

a) Graduates of Breathworks *"Living Well with Pain and Illness"* courses at three centres in the north of England (identified here as B, L and M);
b) Breathworks trainers living in the Yorkshire, North West and East Midlands areas;
c) Breathworks founders.

This sampling frame was selected to provide a spread of graduates who had attended the course in different locations and been taught by different trainers. Graduates included both those who were self-funded and those who had been referred via various funded routes including NHS and local authority pilot projects, and a pain management clinical trial. Breathworks trainers were drawn from a wider geographical area due to smaller overall numbers, but within travelling distance for interviews and/or focus groups. All founders were approached, being a defined group of three people.

5.2.2.2 Inclusion criteria

Data collection was designed as a two-phase process, phase one consisting of in-depth two-stage interviews and phase two of focus groups. The sampling frame for the two phases largely overlapped, with specific inclusion criteria outlined below.

Phase 1: Interviews

Inclusion criteria were that participants should:

a) Consider themselves to have a long-term physical or mental health condition (no medical diagnosis or confirmation was required);

b) Have started attending a Breathworks course at least six months previously;

c) Have attended at least half (i.e. four or more) of the course sessions;

d) Have tried using the mindfulness techniques since attending, but not necessarily found them helpful;

e) Be over 16;

f) Be able to give informed consent;

g) Be able to speak and understand English.

Breathworks' graduates and trainers, but not founders, were invited to participate in interviews. The requirements for six month's minimum time and some experience of trying mindfulness techniques ensured a longer term, experience-based perspective. The minimum attendance requirement ensured adequate exposure to the practices and ideas. From discussion with Breathworks' staff, it was evident that almost all those approached would meet the inclusion criteria. Nearly all graduates and many trainers had LTCs, no-one under 16 had attended, whilst course attendance necessitated a good standard of spoken and written English. The latter would generally have been established during pre-course conversations with the trainers, in which people's expectations and ability to benefit are discussed. This process also reduced the likelihood that anyone lacking the capacity to consent would have attended the course.

Phase 2: Focus groups

Inclusion criteria for the **graduates'** focus group were almost identical to those above, but were widened to include participants who had not tried to use mindfulness since the course. It was hoped this might encourage people with less positive experiences to participate, who were unlikely to have continued practising after the training.

Criteria for the **trainers'** focus group did not include requirements regarding course attendance or use of mindfulness techniques, as these could be assumed to be met. The requirement to have a LTC was also removed, as the intention was primarily to draw on trainers' experiences of training other people with LTCs rather than their own personal experience. Participants were drawn from the same population as for the interviews, with the addition of the Breathworks' founder trainers.

5.2.3 Identification and recruitment of participants

5.2.3.1 Initial consultation and recruitment planning

I met with the founder of Breathworks, Vidyamala Burch, to discuss the proposed research *(NB Vidyamala has waived her right to anonymity, and requested that her name be used)*. She offered her and Breathworks' support for the research, including arranging access to their database and writing a supporting letter to be sent with the recruitment mailing. I then liaised with two other Breathworks workers to develop a procedure for recruitment, as this stage of the process required their assistance to complete. Draft copies of the recruitment materials were sent to these three people for comment, which led to an amendment in the proposed length of the interview and focus groups.

5.2.3.2   Recruitment strategy and process

Following ethical approval (see 5.5), the recruitment mailing was prepared (Appendix B), including a reply slip and stamped addressed reply envelope (later replaced with a Freepost reply envelope to reduce costs). Breathworks' staff added name and address labels, selecting only participants who had attended the course at least six months previously. No other filtering was possible, meaning that a few ineligible people e.g. health professionals who had attended the course, were sent the mailing. Participants were asked to decide whether they met the inclusion criteria and this was checked when initial contact was made with respondents. A telephone conversation, based on a checklist, ensured the inclusion criteria were met and that there were no concerns about people's ability to participate in the research.

A staggered recruitment process was developed to allow management of the response rate and enable theoretical sampling (Charmaz, 2006, Corbin and Strauss, 2008). The timeline for the recruitment and data collection process is shown in Figure 5.1. The first batch of recruitment letters were sent to graduates from centres B and L, and to Breathworks trainers, inviting participation in interviews and/or focus groups. This was a smaller pool of people than at centre M, thus reducing the risk of over-recruitment, and enabling the response rate to be gauged for the larger second stage. It also allowed a more targeted theoretical sampling strategy to be used for recruitment from centre M, as considered below.

Interviews started with Breathworks' graduates, as I considered that the trainers, with a potentially deeper understanding of the concepts behind mindfulness, would provide a more theoretical interpretation of their experience. I decided that this interpretation could over-influence the direction of the analysis, which would not be beneficial to the inductive process of theory development. In view of this, and that there had been sufficient responses from the trainers to potentially form a specific focus group, the trainers were contacted to explain they would be invited to this group at a later stage.

Following the first few interviews, analysis of the data suggested certain experiences were not strongly represented which it would be helpful to explore further. As is discussed in 5.3, a specific request was therefore added to the second round of recruitment letters, encouraging people with these experiences to take part. Following ethical approval, this amended mailing was sent to graduates of courses run from centre M (Appendix C).

As hoped, response rates from the staggered recruitment process produced sufficient participant numbers for interviews and three potential focus groups, two of Breathworks graduates and one of trainers. On this basis it was decided that no further general recruitment was necessary. A specific decision was however made to invite the three Breathworks' founders to participate in the trainers' focus group. Following ethical approval for revised personalised recruitment letters, invitations were sent to the founders, whose responses were then included in the planning of the focus groups.

Full details of the flow of participants through the study are provided in Chapter 6.

Figure 5.1 Recruitment and data collection timeline
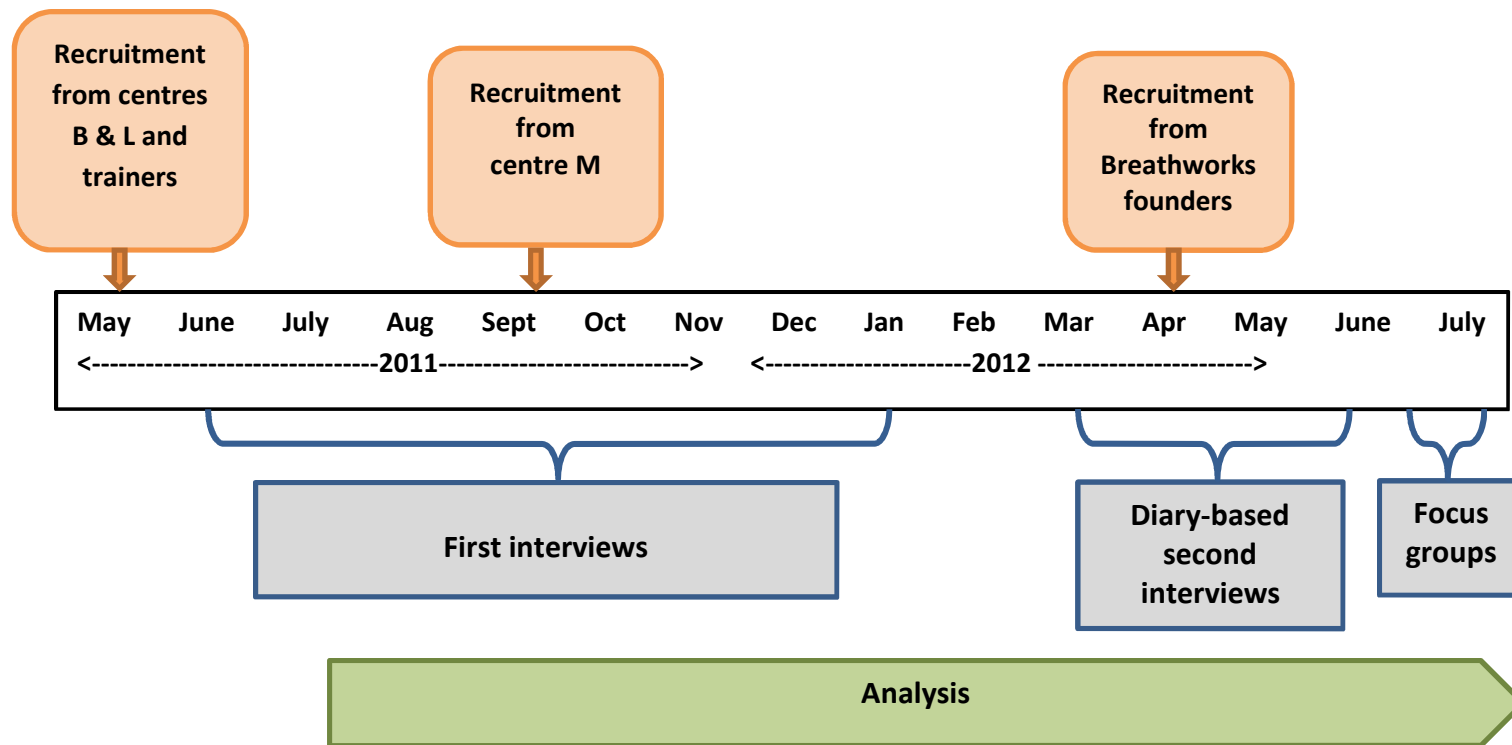
5.3   Sampling strategy, sample size and saturation

As identified earlier, one of the characteristics of GT is its use of theoretical sampling (Glaser and Strauss, 1967, Charmaz, 2006, Corbin and Strauss, 2008), in which sample size and characteristics are not defined at the study outset, but evolve as data collection and analysis proceeds and particular directions of exploration are identified (Kuzel, 1992, Coyne, 1997). Theoretical sampling enables the researcher to select participants who are able to provide information to deepen their understanding of the developing concepts and categories, allowing them to be 'filled out' and new dimensions identified (Corbin and Strauss, 2008). Through this process, it becomes possible to develop a convincing theory that captures the essence of the data in all its complexity (Morse, 1995, Charmaz, 2006). Sampling stops when the researcher considers no new insights are being gained and no new dimensions of the theory and its categories are being identified, a point that is termed 'saturation' (Charmaz, 2006, Corbin and Strauss, 2008).

Although the term 'saturation' is widely stated as a goal in both GT and more widely within qualitative research, there is considerable debate about the both the theoretical and practical aspects of the concept (Morse, 1995, Guest et al., 2006). There are no specific guidelines on what constitutes 'enough' data (Morse, 1995), and it is never possible to be certain that new information would not emerge with further sampling.   Corbin pragmatically suggests that *"eventually a researcher has to say this concept is sufficiently well developed for purposes of this research and accept what has not been covered as one of the limitations of the study"* (Corbin and Strauss, 2008), a point which recognises that practical concerns will almost always impact on decisions regarding continued sampling. There is inevitably also a subjective aspect to this process: Charmaz argues that saturation is *"an elastic category that contracts and expands to suit the researcher's definitions rather than any consensual standard"* (Charmaz, 2001, p689-690). It is therefore important to clarify how decisions were made in this study regarding sampling strategy and saturation.

As far as was possible, a theoretically driven approach to recruitment and data collection was taken (Charmaz, 2006, Corbin and Strauss, 2008), but it was also necessary to make preliminary calculations of sample size in order to plan the study. The detailed nature of qualitative data means that sample sizes are generally recommended to be less than 50 to enable exploration in sufficient depth to identify meaningful conclusions (Ritchie and Lewis, 2003). Creswell (2007) suggests that 20-30 interviews often provides sufficient data for GT research, and on this basis, an initial target was set of approximately 20 interview participants and three or four focus groups.

Once recruitment commenced, concurrent data collection and analysis allowed the identification of categories and themes within the data, so that later stages of recruitment could be informed by these emerging ideas and concepts. It became clear from the initial analysis that there was a very strong core of positive experiences shared by the majority of participants, and it seemed probable that those who had particularly benefitted from mindfulness were disproportionately likely to have responded. In order to understand the range of ways mindfulness may affect people's experience, attempts were therefore made to recruit participants whose experience differed markedly. As noted above, the second

round of recruitment specifically encouraged participation from people with negative or indifferent experiences or who had found barriers to engaging with the course and/or mindfulness practice. As many respondents as possible were then contacted to purposively select for interview people with negative or other notable experiences which might inform the development of the categories and themes. Selection was also directed towards underrepresented groups (e.g. men) or those with health conditions not previously encountered, whose experience might differ as a result. Other respondents were informed that they would be invited to participate in a focus group at a later date. This 'filtering' process continued as the interviews progressed, with decisions being made based on continuing data collection and analysis.

During recruitment it became apparent through conversation with Breathworks' staff that graduates were only entered onto their database upon *completion* of the course; thus those dropping out at an early stage would not receive the recruitment mailing. This obviously impacted on the potential for contacting those who were not satisfied with their experience. Further attempts to understand negative reactions to mindfulness were made through asking interview participants about their observations on other course participants, and through discussion in focus groups about the factors which affected people's ability to engage with the practices. Whilst this was 'second hand' data, the trainers in particular had observed a large number of individuals and could thus provide some insights into this aspect of experience which was obtained to only a limited extent through direct sampling.

As the interviews and analysis progressed, the themes and categories identified in the data were refined, and became clearer and more substantial. New information continued to emerge, but at a diminishing rate. At this point, and in consultation with my supervisors, it was decided that saturation had been sufficiently reached, and that the data gathered provided enough depth, diversity and detail to offer the potential for developing a *"comprehensive and convincing theory"* (Morse, 1995, p148). This decision also took account of the fact that additional data would be collected through the second interviews, diaries and focus groups. Further theory development was also made possible by delaying decisions regarding the composition and questions to be explored by the focus groups until all first interviews had been completed and analysed.

5.4 Data collection

A number of data collection approaches were used, specifically two-stage interviews, diaries and focus groups. This enabled a multi-dimensional picture of people's experience to be built up, with each approach being used at a different stage to facilitate development of theory from the data. Data were collected over the course of 13 months in two phases, two-stage interviews followed by focus groups, as shown in Figure 5.1.

5.4.1 Phase 1: Two-stage interviews

Individual interviews were selected as the primary data collection method, being an approach that can *"yield rich insights into people's biographies, experiences, opinions, values, aspirations, attitudes and feelings"* (May, 2001, p120). The one-to-one setting was

also considered most likely to allow people to share difficult or personal information, including negative experiences of mindfulness and Breathworks.

A two-stage interview process was used, which served a number of purposes. It facilitated the development of greater rapport, which enabled participants to explore and share their experience in greater depth, including sensitive information, and with less concern to present a particular 'public' image (Bowling, 2009). It also supported the GT process of theory development (Charmaz, 2001), enabling particular directions of exploration to be pursued in more depth as they emerged during the research, and thus enabling the refinement of the analysis. As all participants had attended Breathworks at least six months prior to first interview, it was assumed that patterns of mindfulness practice would largely be already established. The second interviews therefore did not focus on exploring changes *between* the two time points in any depth.

The two interviews were initially planned to be approximately three months apart. This was estimated to be the time needed to complete a preliminary analysis of the first interviews and thus enable it to inform the content of the second interviews. A period of ill-health however required me to spread the first interviews over an extended time, which meant that the majority of second interviews were more than six months later, as is discussed further in 5.4.1.2. This offered an unanticipated opportunity to briefly review notable changes in people's practice over a longer timescale.

The interview structure combined elements of both unstructured and semi-structured interviews, the considerable variation in the use of these terms making them hard to entirely differentiate. Unstructured or depth interviews may have no specific questions, but aim to explore one or two topic areas in depth (Britten, 2006), to allow *"respondents to tell their own stories in their own words, with prompting from the interviewer"* (Bowling, 2009, p407), and to explore complex issues and meanings. Their longer, more interactive format also facilitated the development of rapport, as discussed above. An in-depth interview structure is recommended by Charmaz as particularly suitable for use in GT, allowing the researcher to *"take control of their data collection and analysis"* (2001, p676), whilst providing the necessary flexibility to investigate unexpected directions. Semi-structured interviews are also considered to provide an in-depth exploration, but through use of a more fixed set of specific, open ended questions. However, Britten describes it as a *"loose structure… from which the interviewer or interviewee may diverge to pursue an idea or response in more detail"* (Britten, 2006, p13). There is therefore still flexibility within this format to allow directions to be followed that are not included in the interview schedule (Bowling, 2009).

The interview structure drew on Rubin and Rubin's (2005) 'responsive interview' model, which identifies three types of intervention: main questions, follow-up questions and probes. Main questions are pre-planned and provide the basic structure for the interview, ensuring that key areas of interest are covered. Follow-up questions are generated within the interview to further explore particular comments in greater depth and to clarify meaning. Probes are interventions designed to encourage the interviewee to continue talking on a particular topic, and again are developed within the interview setting.

5.4.1.1 First interviews

Participants were telephoned to arrange the interview and ensure they were clear about its structure and purpose. Arrangements were then confirmed by letter or email and my mobile phone number provided to ensure people could change arrangements at short notice if necessary, an important consideration given the health of many participants. Participants were informed that travel expenses could not be offered.

Interviews began with informal conversation, following which participants were asked to complete a consent form and socio-demographic information (see 5.4.3). Following a check of sound levels, the formal recorded interview then began. Broad, open questions were designed to explore a number of areas in depth: participants' perspectives on their health history and current symptoms; the impact of their health condition on their life; their experience of Breathworks; and their subsequent experience of mindfulness practice (see Appendix F). A series of prompts were developed to be used if appropriate to elicit further information.

The structure was used flexibly, with time and space allowed for particular topics or directions raised by the participants to be followed up (May, 2001). In addition, although the main topics remained unchanged, the questions evolved to some degree over the course of the interviews in line with GT methodology. For instance, the subject of acceptance arose on a number of occasions as an important issue, which led to this being specifically explored in later interviews. Similarly, where participants mentioned a specific faith background, this was pursued to identify how it had impacted on their experience of Breathworks and its Buddhist context. The interview concluded with distribution of the diary and explanation of the next stage of the process.

Interviews were mostly conducted in participants' homes, with three people choosing to meet at other locations for reasons of convenience. The length varied, but recorded time was generally between 1 – 1.5 hours. Allowing for introductions and often a short break part way through, overall meeting time was often approximately two hours.

One interview was arranged with a participant experiencing highly problematic and distressing symptoms, together with emotional stress relating both to her condition and other circumstances. In this case, the interviewee became too distressed to talk about her experience, and asked for recording to be stopped. After some unrecorded conversation I suggested postponement of the interview, although subsequent attempts to meet or speak further were prevented by her illness.

5.4.1.2 Second interviews and diaries

Second interviews focused on understanding participants' everyday experience of living with their condition and the ways, if any, that practising mindfulness affected this. To facilitate this, participants were asked to complete a diary for the week prior to the interview. Attempts were made to contact and arrange second interviews with all participants who had completed a first interview, and this was successful in most instances. Participants were reminded of the structure and purpose of the interview, and of the use of the diary. An interview date was agreed, and participants were offered an

email or text message reminder to prompt them to start the diary; this was particularly useful when interviews were arranged some time ahead.

The diary had two sections (see Appendix G). The first section was a record of participants' mindfulness practice for the week; this was collected in and analysed to explore people's patterns of practice, including frequency and duration of formal meditation and use of informal mindfulness practice. The second section provided space for personal reflections on specific experiences during the week; this remained confidential to the participant, and was used to enable exploration in the interview of people's practical uses of mindfulness rather than to generate further written data for analysis. Completion of this section was therefore optional, to reduce the burden on participants, but offered an aid to recall which was potentially of particular value for people with memory problems. It was hoped that this use of diaries would bring into consciousness decisions and experiences which might be a very familiar part of life. Paterson and Thorne considered that a similar process of two interviews and an audio-recorded 'diary' helped to reveal *"participant's decisions in a current, rather than a retrospective or simulated, manner"* (2000, p150), and this proved true in this study. An unexpected outcome was the benefit identified by some participants in deepening their understanding of their experience, discussed in 7.4a.2.6.

The second interviews had a greater degree of structure, but retained both in-depth and semi-structured aspects, with broad main questions (Appendix H). Time was spent at the beginning informally 'catching up', and finding out about any significant changes since the previous meeting. The formal recorded interview commenced with brief discussion of people's experience of completion of the diary, followed by in-depth exploration of particular incidents, either as written in the diary or recalled by the participant if the diary had not been completed. Questioning took different directions depending on the participant and the issues raised. In some cases particular points from the first interview were also pursued further. The interview then moved onto a more structured phase, exploring some or all of the specific questions developed from the analysis of the first interview data (Charmaz, 2001). Once this phase was completed, recording was stopped and the remaining time was used to share and discuss with participants the initial findings and ideas from the developing analysis, including an outline 'model' of the mindfulness experience. Feedback from participants led to amendments to the 'model' as the interviews progressed, helping to confirm and refine my directions of thinking (see further discussion on respondent validation in 4.6.2). The interview concluded with providing participants with information about the next stages of the research and how they would be informed of its findings.

Most interviews again took place in participants' homes, with two at the university. Recorded interview time was generally approximately an hour. There was however more non-recorded time than at the first interview, both before and after the recorded section; thus overall meeting time was quite similar. Whilst first interviews had been spread over a long period, as noted above, second interviews were undertaken in a much more concentrated timeframe. This meant the interval between participants' two interviews varied considerably from 4.5 to 9.5 months, with 13 (65%) being six months or more. Details of individual participants' interviews are given in Figure 6.3. All second interviews were completed before the focus groups took place.

5.4.2   Phase 2: Focus groups

Focus groups offer a number of benefits to the research process. Their particular strength is their ability not just to discover the range of perspectives that people have on a topic, but to gain insight into how these perspectives are generated through the group interaction (Liamputtong, 2011). Observing the behaviour and discussion between the participants offers valuable insights into the 'culture' of a group or organisation, revealing aspects of its core values, language and norms which are not readily accessible through other data collection methods (Morgan, 1997, Bloor et al., 2002, Pope and Mays, 2006). Focus groups are sometimes viewed as an efficient way to gather a wide diversity of perspectives in a short time, but the group setting can encourage conformity and limit the depth of data obtained about individual experiences (Morgan, 1997, Bowling, 2009, Liamputtong, 2011).

Focus groups are commonly used in combination with other methods, both quantitative and qualitative, with a range of purposes (Morgan, 1997, Bloor et al., 2002, Liamputtong, 2011). In this study, the focus groups were intended to provide an opportunity to pursue questions that arose during the first phase of data collection and analysis (Morgan, 1997), to gather additional information relating to underdeveloped themes, and to test initial ideas and findings with a wider group of participants (Bloor et al., 2002). The focus groups therefore formed part of GT theory development process, refining the ongoing analysis (Charmaz, 2001, Birks and Mills, 2011). As discussed in 4.6.2, they were not a means to 'validate' the findings from the interviews (Bloor et al., 2002). Reflecting these purposes, the groups had a number of clear foci for discussion rather than being a more open exploration of participants' experiences (Morgan, 1997, Liamputtong, 2011). They did however also provide an opportunity to discover more about how people talked about their experience of learning and practising mindfulness, what they identified as important, and what degree of consensus there was around these issues.

Focus groups were also included in the data collection process to widen participation in the research, particularly for Breathworks' graduates. They potentially enabled inclusion of a different group of participants who were unable or unwilling to participate in interviews, thus broadening the range of perspectives and increasing the transferability of the findings. In practice, however, this was not a significant factor, as is now discussed.

5.4.2.1   Composition and number of groups

As noted previously, the recruitment process generated sufficient participants to establish separate focus groups for Breathworks' graduates and Breathworks trainers and founders. This offered the advantage of some homogeneity in each group in terms of participants' levels of experience, helping to create a safe environment where people felt confident to contribute (Krueger and Casey, 2000, Liamputtong, 2011). In particular, it minimised the potential sense of hierarchy between trainers and graduates which could inhibit both from speaking freely in a combined group (Morgan, 1997).   This point was also considered in relation to the potential impact of the founders' presence within the trainers' focus group. I decided to invite the founders to this focus group based on my perception of a very 'flat' structure within Breathworks, the impracticalities of running a separate group for these few key individuals, and the potential value of their contribution to the interaction within a

wider group. The latter consideration was particularly significant, as the founders could be assumed to be influential in creating the 'culture' of Breathworks, and this was most likely to be revealed in a focus group discussion.

Participants in phase one were not invited to focus groups. This both increased the overall number of participants, and ensured none of the focus group members had a pre-existing relationship with me which could complicate the group dynamics. With regard to group composition, almost all study participants expressed willingness to be involved in either phase of the study; thus there was no clearly distinct population relative to the interview participants from which to draw. This was further confirmed in respect of Breathworks' graduates through the sampling process described in 5.3. Initial conversations to select participants for phase one revealed strongly consistent themes across people's experiences, with a high level of consensus around the beneficial effects of mindfulness. As participants with the most divergent experiences were purposively selected for interview, this also had the effect of increasing homogeneity among those who remained to be invited to the focus groups.

As noted in 5.2.3.2, all the trainers were specifically asked to participate in a focus group. It was clearly reasonable to assume some consensus around mindfulness as a positive experience within this group. I was however aware of other potential areas of difference, particularly health status, as having a LTC was not a requirement for participation in this part of the study.

The geographical spread of potential participants was reviewed to determine the most convenient locations for meetings. Based on this, it was decided to hold two meetings in the same location, one for trainers and one for graduates, the remaining graduates being too widely scattered to organise a third group. All graduates were therefore invited to one meeting.

5.4.2.2 Focus group process and structure

Invitations were sent to all potential participants, offering a number of dates and asking them to confirm their interest and availability. This produced a quick initial response from the majority, and the remainder were contacted where possible. All participants were informed of the agreed dates, and final confirmation was sent approximately two weeks before each group. This included an information sheet (Appendix J) giving details of the venue, the meeting and outline topics for discussion, together with copies of the consent form and socio-demographic data form. A number of 'no-shows' for the graduates' group prompted me to send a further reminder to the trainers shortly before the meeting: as this was a unique and much smaller group, a good attendance rate was of particular concern.

A Buddhist Centre was used for both groups, as this was an accessible venue already known to many participants who had attended or delivered training or there. I considered whether a more neutral venue was needed, but was aware that none of the potential participants had negative experiences which could deter them from coming to the Centre. Furthermore, having heard many positive comments about the venue during the interviews, it seemed this, together with its familiarity and central location offered considerable advantages and possible incentives to attend.

The focus groups took place after the interviews were completed, with the graduates' focus group occurring first to allow any points from this group to be explored with the trainers. An outline topic guide was developed for each focus group (see Appendices K and L). Questions were designed to explore specific issues of interest identified in phase one, in order to refine and develop the analysis. As prior ethical approval had to be obtained for these topic guides, questions were largely based on analysis of data from the first interviews.

Each group was scheduled to be approximately 1.5 hours of recorded time, with additional time for arrival and conclusion. Participants were also offered the opportunity of a break during the discussion to facilitate their comfort and involvement, and this was requested by the trainers' group. I acted as moderator for both groups, and was supported by a researcher colleague who provided practical help. Prior to starting, copies of the consent and socio-demographic forms were circulated and completed, together with expenses claim forms. Light refreshments were available during the meeting. Before starting recording, I explained the place of the focus groups within the research process, outlined 'ground rules' for the sessions, and answered questions. I also introduced and asked the group to agree definitions of key terms relating to the research. Introductory questions were used to gather basic information such as time since attending training, and to ensure everyone had spoken (Krueger and Casey, 2000, Liamputtong, 2011). Through this process, I ascertained that two of the graduates already knew each other, and most trainers had well-established relationships.

The key questions were then explored, based on the planned schedule but using additional prompts and probes to pursue particular issues or invite participation from other members. I concluded by asking each person in turn if they had anything further they wished to contribute, and then explained the next stages of the research process and how they could be kept informed of its outcome.

5.4.3   Socio-demographic data

Socio-demographic data were gathered on a self-report form (Appendix D) at the start of the first interviews and the beginning of each focus group. Additional information regarding participants' health, employment status, funding for course attendance and time since participation was ascertained during both the first and second interviews and to a more limited degree during the focus group meetings. These data were used to generate information regarding participant characteristics in Chapter 6. No information was obtained from health professionals.

5.4.4   Recording and field notes

All interviews and focus groups were digitally recorded to ensure a comprehensive record of the verbal interaction was obtained and to avoid selective recall of information at later stages of the analysis (Halcomb and Davidson, 2006). Written notes were made as a back-up, to note particular actions or gestures which would not be apparent on an audio recording, and to help attribute comments within the focus groups. Participants were

informed and asked to consent to recording prior to the date of the interview or focus group. A check of sound levels was made at the start of the interviews, which also provided an opportunity for the participant to become used to the recorder before 'officially' starting. Recorders were of a high quality and sensitivity, which allowed them to be placed unobtrusively. For the focus groups, two digital recorders suitable for group discussion were used simultaneously to ensure recording was adequate for transcription and to provide back-up in case one device failed. Participants generally appeared at ease with recording, and it was a familiar experience for me, which may also have contributed to this. On one occasion a participant asked for the recorder to be switched off briefly to recount 'off the record' an experience not directly relevant to the interview.

Written field notes and reflections were made as soon as possible after each interview or focus group, usually within a few hours. These served a number of purposes:

a) to record my observations of the setting and participants, which both provided contextual information for the study and a reminder of details in order to bring the experience to mind more clearly when reviewing the data;

b) to review the question schedule and my own interviewing skills, and identify any changes needed for future interviews;

c) to identify any areas of interest or uncertainty which needed to be explored at a later stage of the research;

d) to reflect on the content and process of the interview or focus group and my reactions to it in order to gain greater insight into the experience and consider possible themes and patterns within it.

These notes therefore contained elements of both field notes and memos, i.e. observations, and reflection and developing thinking on those observations.   In practice, there is no sharp distinction between these activities, as all observations contain an element of interpretation and conceptualisation, a point acknowledged by Corbin (2008). However, she does distinguish between *"observational notes"* (2008, p124), point a) above, often written whilst still in the field; and *memos* which are generally lengthier, more complex and analytical, and written at a later stage, point d) above. Whilst recognising the difference between these two activities, and that more developed memos were written later, I found both happened simultaneously in my initial reflections, and it did not seem beneficial to separate them. An example is shown in Figure 5.2.

Figure 5.2 Extract from interview field notes/reflections

This was altogether a very different setup from most of the ones I've been to – much more working-class I would guess [….] Not a big flat – the two women disappeared off into another room to let us do the interview, coming through only to make a drink [….] It would have been interesting to talk to them about what they've seen and experienced in terms of the change in [name] – I would quite like to talk to some carers or family members to see whether they see the same scale of difference as some people seem to describe. Not that I don't believe what people are saying, but sometimes you can feel very different inside without it being totally apparent on the outside. And, if it does make a difference, or they can see a difference, I wonder what that experience is like - to see that difference – does it make them curious to try it themselves? Are they just pleased that their partner or family member is being helped? Or what? This would be a very interesting thing to explore.

5.4.6 Transcription

Using GT, with its focus on working directly from participants' experiences, I considered it essential to produce verbatim transcripts (Halcomb and Davidson, 2006) for analysis. Due to unexpected health problems, I was unable to transcribe the majority of the interviews myself. This led to the employment of a number of transcribers over the course of data collection. All the transcribers had previous experience of similar work, and had a clear understanding of confidentiality and the need for a verbatim record of the interviews.

Discussion of the first few interviews with the transcriber led me to consider the level of detail that needed to be transcribed. A number of authors (Sandelowski, 1994, Oliver et al., 2005) recommended considering the purpose of the transcript in relation to the chosen methodology, pointing out that an approach such as GT focuses more on the *information content* of communication than the details of the *language structure*. As a result, I drew up guidelines to clarify and standardise how the transcripts should be prepared. These tried to balance retaining the authentic voice and speech pattern of the participant, whilst avoiding obscuring the overall sense of their experience through inclusion of too much detail such as *"conversation fillers"* (MacLean et al p116).

To maintain quality, transcripts I did not produce were checked and amended by reading them through whilst listening to the recording. In two cases where participants had speech difficulties, I transcribed the interviews myself and sent the transcript back to the participant for review, as I considered there were particular concerns about the accuracy of the record.

Transcripts were not generally offered to participants, although the option was offered on a few occasions where there were concerns regarding confidentiality as discussed in 5.5.3. A number of considerations affected this decision. Firstly, reading a transcript is a time consuming and potentially unsettling experience. It often reveals that speech is much more disjointed and 'messy' than expected and, particularly if the topic is a sensitive one, may cause the participant to revisit difficult experiences in an unhelpful way (Forbat and Henderson, 2005). Secondly, from a philosophical perspective, I considered the transcript represented a record of the participant's perspective *on that occasion*, and this perspective would change with time and context. The process of 'checking' would therefore become one of adding more data which, while equally valid, could not confirm the accuracy of the initial record (Poland, 1995, Forbat and Henderson, 2005). I considered the second interviews provided a more effective means to develop understanding of participants' experiences.

5.5   Ensuring ethical research practice

A number of key ethical principles were identified in 4.5, and the ways these were applied to the study are now discussed. An application, reference number 10/H1313/96 was made to Leeds Central Research Ethics Committee and approved on 10 December 2010. NHS ethical approval was required as some Breathworks programmes had been delivered in an NHS setting. As the research progressed, four further amendments were approved:

Date	Type of amendment	Purpose
5/5/11	Minor	Recruitment of transcriber to research team
19/8/11	Substantial	Change to second stage recruitment materials to target participants with particular experiences
23/1/12	Minor	Amendment of study end date
21/3/12	Substantial	Recruitment of founder trainers to focus group Approval of focus group question schedules

5.5.1 Informed consent

To ensure potential participants could make an informed choice about their involvement in the research (NRES, 2009), they were sent full details including an information sheet (Appendix B) outlining what the research involved and how to complain or withdraw from the study. My contact details were provided to give people the opportunity to ask further questions. To prevent any feeling of coercion to participate, no deadline for response was given and no further contact was made with non-respondents following the initial mailing.

Interview participants were telephoned to ensure their understanding, explain the formal consent process, and answer questions about the research. The consent form (Appendix E) was then sent, allowing time for review. At the first interview, the consent form was discussed and signed prior to commencing recording. When contact was made to arrange second interviews, participants were reminded of the option to withdraw, and that the data from the first interview would still form a valuable part of the research. Questions were invited at the start and finish of each interview.

For focus groups, consent forms were sent to participants prior to the event together with an information sheet. Participants could review and complete the form before the meeting, and further copies were made available at the start of the focus group. Prior to starting recording, participants were offered an opportunity to ask questions.

5.5.2 Facilitating participation

Efforts were made to reduce barriers to participation which could particularly affect people with LTC, and prevent their experiences from being included. Information was offered in large print and digital format to increase ease of use. Interviews were generally conducted in people's homes to reduce travel demands and create a more relaxed environment. Participants were offered the option of conducting the interview in shorter sections, and during the interviews I tried to remain aware of people's levels of energy and comfort, generally suggesting a short break part way through, which was often welcomed. In one instance, where an interview could not be completed, text message and email contact enabled me to include their perspective to a limited degree.

Focus groups were held in an accessible venue well known to many participants. Travel expenses and refreshments were offered. Participants were given the option of having a break part way through the meeting, and encouraged to do what was necessary to ensure their comfort e.g. move around or take time out.

5.5.3 Confidentiality

Ensuring confidentiality regarding participants' identity and personal information was of key importance (MRC, 2005), and was addressed in a number of ways.

To ensure I had no access to information about the identity of potential participants, the recruitment mailing envelopes were taken to Breathworks offices for their staff to add address labels. All responses came direct to me to ensure Breathworks had no information regarding anyone's involvement in the research. One respondent identified themselves as known to me and, following discussion, we agreed their participation would not present any difficulty (although they did not eventually participate).

Each participant was allocated a code and pseudonym, and this information was stored on a password protected computer. The code was used to name all documents relating to the participant. During transcription, the pseudonym was used and any identifying locations and names removed. On a few occasions, participants expressed concern that details of their experience were distinctive enough to make them identifiable. In these instances we jointly agreed the steps to be taken to anonymise them, including removal of any potentially identifying features, particularly condition-specific information. I offered these participants the option to review the completed transcript, but the discussion seemed to provide sufficient reassurance as this was not requested.

5.5.4 Data protection

The requirements of the Data Protection Act 1998 were followed with regard to maintaining the privacy and protection of participants' information, including ensuring data were kept and processed fairly and for a specific purpose, was up to date and not excessive, and kept securely for no longer than necessary (ICO, 2013).

Interview and focus group recordings were downloaded and deleted from the digital recorder at the earliest opportunity and saved onto the University computer system, which has a secure server and password protected access. Encrypted, password protected memory sticks were used to transfer data to and from the transcribers. Electronic data were stored on password protected computers accessible only to the research team. Paper data were stored in a locked filing cabinet in a secure office at the University. Following University policy, data from the project will be kept for two years after completion of the PhD viva, to allow time for academic challenge.

5.5.5 Protection from harm

Whilst most research does not lead to harm, the importance of minimising risks and making potential participants aware of these was considered (NRES, 2009), together with the related concern of managing risks to myself as the researcher.

Research participants

Discussion of sensitive topics such as health problems and their impact has the potential to trigger distress, and this was brought to people's attention on the information sheet, together with the offer of referral to other support should this prove necessary. The initial phone conversation with potential participants also provided an opportunity to ensure

there were no concerns that people's physical and/or mental health problems could affect their ability to participate in the research without risking harm to themselves.

During the interviews, a number of people became emotional. I considered this an appropriate response to the situations they were describing, and it did not prompt concerns about their overall wellbeing, perhaps because the distress often related to past rather than present experiences. Many people in fact identified participation in the interviews as helpful and beneficial, a point discussed in 7.4a.2.6. An exception to this was a participant who became distressed during an interview, which led to it being suspended as explained in 5.4.1.1. I discussed this situation with my supervisors and made some further contact with participant. Their subsequent admission to hospital provided some reassurance that they were receiving appropriate care and we agreed that no further action on my part was necessary.

Researcher

A risk assessment of the research was carried out by the University prior to data collection commencing, and the issue of personal safety identified, given that I would be travelling alone to visit participants in their homes. A personal safety policy was followed, with a colleague being informed of the date, time and location of the interviews, and provided with contact details for myself and the interviewee. Contact was made before and after each interview at times agreed in advance, with a planned course of action being in place should contact not take place. There were no instances where I felt at any risk, but the post-interview contact provided a useful 'debrief' on a number of occasions.

5.6   From data to concepts: the process of data analysis

This section presents the process used to analyse the interview and focus group data. It begins by identifying the analysis strategy, the approach to coding, and the tools used to facilitate the analysis. This is followed by a detailed discussion of how these tools and strategies were implemented at each stage of the process.

5.6.1   Analysis strategy

Consideration was given to how the data from the two phases of the study should be analysed, and this led to a decision to analyse the data from the interviews together with that from the graduates' focus group, and to analyse the trainers' focus group data separately. The reasons for adopting this strategy were based on the nature of the data collected through the interview process, and the similarities in characteristics between the graduates participating in the interviews and focus group, as will now be discussed.

As discussed above, phase one of data collection was designed to explore participants' experiences through two-stage interviews. Time was allowed between the interviews to enable analysis to take place in line with GT process, this then informing the direction and detailed content of the second interviews. The purpose of the second interviews was not therefore primarily to explore *changes* in people's experiences, it being assumed that the length of time since attending Breathworks would mean that patterns and perceptions

were generally well-established. This assumption was strongly borne out, even with the extended interval between the two interviews noted in 5.4.1. Most people's health and life situations were broadly unchanged; some had experienced worsening of their symptoms or were facing new challenges in life; others had seen some improvement. All had continued to practice mindfulness and to meditate to a varying extent, something I had not assumed would be the case. There was a striking consistency in participants' accounts, with people frequently using the same phrases or returning to similar themes to describe their practice and how mindfulness affected their experience of living with a LTC.

Reviewing the interview data, it became clear that it represented a coherent whole, with the second interviews providing refinement and development of the themes identified in the first. In particular, the diary-based discussion provided reinforcement and detailed specific examples of the experiences described in the first interviews. The use of questions based on initial analysis also enabled themes and ideas to be pursued in greater depth, and for new dimensions of these to emerge, thus furthering the theoretical development of the analysis. As a result of this coherence, it was considered that the data from the two stages of the interviews needed to be analysed as a whole to preserve its integrity and prevent key themes being obscured through separate analyses.

With regard to the graduates' focus group, as discussed in 5.4.2.1, it became apparent that these participants did not differ from the interview participants in their characteristics or in their experiences of mindfulness. Participants were drawn from the same sample and, from the initial conversations which took place as part of the purposive sampling, it was clear that there was a strong similarity to the generally positive experiences recounted in the interviews. It was thus anticipated that no significant new themes would arise from this group, but that it provided an opportunity to review and explore these themes in more depth and through group interaction. This expectation was borne out in the focus group discussion, where participants shared experiences closely reflecting those described in the interviews, as highlighted in my reflections in Figure 5.3 below.

Figure 5.3 Reflections on graduates' focus group

All overwhelmingly positive and no real inconsistencies between them. I've no idea if these would have emerged with more discussion. There was certainly differences in what people found useful as tools e.g. some people relating to kindly awareness and some people not, one person not getting on at all with the CDs and others really liking them. However what they all got from it did seem similar – I think different people expressed different aspects of that e.g. some people talking a lot about letting go of fighting to get better, someone else identifying the importance of feeling more connected with other people, someone else identifying reducing symptoms and getting themselves back – all of which are things that are already present in my data. (5/7/13)

The original intention was that the graduates' focus groups would offer a more divergent range of experiences and therefore be analysed separately. For reasons which have been discussed above, however, this intention was not fulfilled. On reviewing the data from this group, it did not appear to represent a distinct and separate set from that collected in the interviews. Whilst recognising that focus groups represent a different data collection method from individual interviews, and the information gathered therefore has a different

status, these considerations led me to decide to integrate the analysis of this data with that from the interviews, together with my reflections on the process of the focus group.

In contrast, the trainers represented an identifiably different group. Although the majority were living with LTC and practising mindfulness, they brought a perspective based on their theoretical and conceptual knowledge of Breathworks developed through their training. They also had experience and insights drawn from working with many Breathworks participants over a number of years. The questions and issues discussed in the focus group reflected this difference, as did the way in which the group operated. This material was therefore analysed and reported separately. As the focus group also addressed further dimensions of the same research question however, the coding built on and added to the existing structure developed in NVivo. Versions of the coding frame before and after coding this data were retained to enable the influence of the trainers' group on the analysis to be identified.

5.6.2   Selection of coding approach and definition of terms

The process of coding is defined by Charmaz as *"naming segments of data with a label that simultaneously categorizes, summarizes, and accounts for each piece of data"* (Charmaz, 2006, p43). Codes are considered the fundamental building blocks from which theory is developed, each one representing a 'unit of meaning' indicating a concept or idea that is present in the data (Birks and Mills, 2011, Charmaz, 2006, Corbin and Strauss, 2008). A range of approaches to coding are outlined in GT, based on different interpretations of the method. All share a basic understanding however that coding moves through increasing levels of abstraction, initially identifying low-level concepts which remain close to the data and progressing to higher-level concepts, generally termed 'categories', which explain and provide theoretical insight into increasingly larger segments of the data (Birks and Mills, 2011, Charmaz, 2006, Corbin and Strauss, 2008). Within this thesis, I have used the terms 'code' and 'category' as described here; however I have also introduced the term 'theme'. Whilst this latter term is not widely used in GT, it is offered as an alternative to 'category' by Corbin and Strauss (2008), and I have used it for clarity to specifically identify the highest level categories in the analysis.

As noted in 4.4.3.2, I explored the range of approaches to coding proposed by various GT authors, and chose to base my work on Charmaz's (2006) two-stage model of open and focused or selective coding.   This method offered considerable freedom and flexibility, whilst at the same time giving a clear sense of direction towards identifying *"which initial codes make the most analytic sense to categorise your data incisively and completely"* (Charmaz, 2006, p57). The process was also informed by the concept of 'types' of coding (Coffey and Atkinson, 1996, Richards, 2009), in particular Richards' (2009) classification of descriptive, topic and analytical coding. This recognises that the data can be organised in a variety of ways: labelling simple factual information (descriptive coding); identifying the main areas of interest (topic coding); or identifying concepts and interpretations within the material (analytic coding). This idea helped reinforce the purpose of coding, reminding me to 'take off' or 'move up' from the raw data towards a more analytical and theoretical interpretation of it, as noted in the previous paragraph.

Charmaz's recommendation of coding for actions was adopted (Charmaz, 2006), leading to an emphasis on creating verb-based codes (e.g. becoming kinder to self, letting go of struggling). This approach seemed very appropriate to the research, where participants recounted a number of processes of change connected with their experience of illness and mindfulness. Coding for actions created more dynamism, encouraging me to ask, as Charmaz suggests, 'What is happening here?' and therefore focusing on the meaning and essence of the code being created. Similarly, Richards' questions *"What is [this] particular passage about?"* and *"Why am I interested in that?"* (2009, p103) helped me focus on the *purpose* of coding, which could easily be lost in the volume and complexity of the data.

5.6.3 Data management tools and strategies

5.6.3.1 Software

NVivo 8 (QSR, 2008) software was used throughout the process of creating and developing the coding structure. Whilst recognising the limitations of computer programmes, I found NVivo offered the potential to explore, compare and link data in creative and flexible ways which are not possible with manual methods (Richards, 1999, Bazeley and Richards, 2000).

NVivo's free node and tree node structure proved helpful for managing the development of the coding structure, in particular the movement from open coding to selective/focused coding discussed in detail below. Free nodes were initially used for all coding to represent the topics and ideas identified within the data. This allowed maximum flexibility for exploring the information in different ways, and reflected the open coding stage. As more overarching categories and themes were identified amongst the data, these were moved into or created in the tree node structure, with all relevant free nodes becoming 'branches' of these nodes. This reflected the movement towards focused/selective coding and a developing sense of structure in the analysis. I used NVivo's facility to retrieve all data associated with a particular node to review how accurately it reflected that dimension of experience. This frequently led to renaming or restructuring of codes, a process which continued throughout the analysis, as explored further below.

5.6.3.2 Manual and visual approaches

One limitation of NVivo is that it does not readily provide visual representations of the data. This made it difficult to identify patterns and relationships within the coding, which I found essential to the analysis, and therefore used a number of additional strategies. Lists of nodes were printed off to enable the coding as a whole to be reviewed. This helped to identify duplications as well as places where data were becoming 'denser' i.e. recurring themes. Mind maps were used to visually represent the key themes in interview participants' experiences (see example in Appendix M). Mapping was also used to explore aspects of the data, such as the dimensions of a particular theme or linkages between different codes and categories, as shown in Figure 5.4. Later, the main themes and categories were written out on 'post-it' notes to explore possible relationships between them. These strategies reflect the 'clustering' approach advocated by Charmaz (2006) to identify non-linear relationships in the data, and were essential in exploring its complexity.

Figure 5.4 Mapping of a section of coding

5.6.3.3 Memo-writing

Memos form a key part of the GT process, providing a means to reflect on and progress the analysis (Charmaz, 2006, Corbin and Strauss, 2008). As described in 5.4.4, I wrote memos throughout the research process, and particularly during this stage. This helped me to reflect on and develop the emerging coding structure and theory, to clarify relationships between codes, and to differentiate between or combine similar codes. At a later stage, memos were used to explore how the analysis connected to wider literature regarding mindfulness and the chronic illness experience. It also enabled me to reflect on my own experiences and how these informed the research process. NVivo was used to store and develop memos, and to link them to the primary data, codes and categories, and to other memos. This allowed considerable cross-referencing, which was particularly valuable given the complex and sometimes overlapping relationships between the various aspects of the data. Memos were built and developed over time, with additions and changes being made as the coding structure was refined and new ideas and connections were explored.

5.6.3.4 Use of metaphor

Metaphors are identified by several writers as a valuable tool to support the process of theoretical integration in the later stages of analysis (Dey, 1993, Birks and Mills, 2011). Whilst caution is needed to ensure metaphors do not force or distract from the data, they can support theory development *"by clarifying relationships and providing labels for various components"* (Birks and Mills, 2011, p126) and help with the identification of patterns in the data. A metaphor can also powerfully communicate the core of participants' experiences in a way which is both abstract and grounded. At various stages during the research, I explored the parallels between living with a LTC and undertaking an unwanted journey to an unfamiliar country. This metaphor was eventually used to create an integrated structure for the analysis, as is discussed in 5.6.5.3.

5.6.4 Other input into the analysis

5.6.4.1 Supervisors

All data were coded by me, which ensured a consistency of approach to the analysis. In order to obtain other perspectives, and to provide feedback on my coding strategy, two early interviews were also independently reviewed and coded by my supervisors. On meeting to discuss our findings, a general consensus was found around the key themes, and a number of possible directions were also identified for further consideration. Subsequently, we used a similar process to review an anomalous first interview and explore possible interpretations of the person's experience. On a number of occasions, we also discussed my evolving coding structure and ideas. This helped to clarify the purpose and direction of coding, ensuring it remained focused on addressing the research question.

5.6.4.2 Literature review

As highlighted in 4.4.3.2, there is considerable debate within GT about how and when existing literature should be explored and referred to within the research. There is however broad agreement that concepts and theory should be developed from the data rather than being based on pre-existing ideas, which leads to a general recommendation that any thorough review of the literature should be delayed until after the grounded theory has been developed (Glaser and Strauss, 1967, Strauss and Corbin, 1998, Charmaz, 2006, Birks and Mills, 2011). Throughout the process, I therefore tried to maintain the *"precarious balance between the two sources"* of existing theory and personal insight (Glaser and Strauss, 1967, p253), recognising that both would contribute towards the development of my thinking.

As noted previously, a scoping review of the mindfulness literature was carried out as part of the development of the research question. I also had a pre-existing familiarity with mindfulness and Buddhism which, as explored in Chapter 9, provided me with theoretical sensitivity that had both benefits and challenges for the research. Once I commenced recruitment and data collection however, for both pragmatic and theoretical reasons the literature was put aside to a substantial degree. However, I kept some awareness of new mindfulness research being published and read selectively to stay informed of potentially relevant developments.

The other substantial field of literature relevant to this research related to living with chronic illness, and this was approached in a different way. This literature is located across a number of disciplines, including psychology, sociology, anthropology and the health sciences (Thorne et al., 2002). As I did not have a previous 'disciplinary home' in any of these disciplines however, I did not begin the research with a detailed awareness of this body of work. As a result, I was able to make a deliberate decision not to engage with it in any depth before starting data collection, but rather to see what ideas and concepts I identified from my analysis. As data collection and analysis progressed, however, and my ideas developed, I felt it would be helpful to explore existing work in this area, and read purposively to get a sense of how my ideas related to this wider body of knowledge. I found this greater theoretical sensitivity helpful in informing the development of questions for the second interviews, and in challenging me to consider a variety of understandings of

participants' experiences. Additionally, at a later stage, I selectively read work regarding the concept of transition (Meleis et al., 2000), and found that the link between illness and the migration experience had already been explored, which supported my developing thinking in this area.

5.6.5   The process of coding and analysis

5.6.5.1   First interviews

Consistent with GT methodology, (Strauss and Corbin, 1998, Charmaz, 2001, Charmaz, 2006), data analysis began shortly after the first interviews had been completed and continued throughout the data collection process. I began with a process of open coding of each interview transcript, using line by line coding (Strauss and Corbin, 1998, Charmaz, 2006) to ensure that all relevant material was coded, and to break the text down into 'units of meaning' as described in 5.6.2. To capture the detail of content, multiple codes were assigned to much of the text, which reflected the complexity of the content. Where the exact meaning of a section was not yet clear, I coded for a range of possible interpretations. Figure 5.5 gives an example of a section of coding part way through the analysis process, when many of the codes had already been partly grouped into provisional categories.

As discussed in 5.6.2, I also created different types of codes based on Richards' model (2009). For each interview participant, *descriptive coding* was used to create a 'case' in NVivo, using information drawn from the socio-demographic questionnaire and the interviews. This was exported to Excel to generate information regarding the sample characteristics.   Further descriptive codes were created within NVivo's node structure to identify details of participants' health conditions and previous meditation experience.

I found that *topic coding,* identifying key topics in the text, seemed inevitably to move into *analytic coding,* exploring the data from a more conceptual perspective. These stages were thus not clearly differentiated.

Figure 5.5 Extract from first interview, showing coding

JL: OK, and would you say it's changed how you see yourself and feel about yourself? Helen: Mmm, a lot, umm, I'd say in some positive ways as well as negative ways because I think before I was always very driven and focussed on my academic work and trying to achieve stuff and I don't know whether this is actually having the, …, this happen to me or whether it's actually the kind of the Breathworks and stuff, I'm not sure which of it, I think it probably is the Breathworks stuff, that umm, that's had a more positive way in how I, how I feel about myself and I'm less focussed on academic stuff and more on enjoying myself and looking after myself and relationships with other people, umm, but, in the pain itself I think has changed things, because I was only (age) when it happened, and I think at that point you're not very exposed to that kind of suffering and you don't, I'd not met any people with disabilities or pain or illness, and yet suddenly you're thrown into this world where you go to pain clinics and you see all these problems, and, it's just normal, so, .., yeah, …umm, and I suppose physically it reduces the level of confidence that I have that I can do things and go anywhere and do anything yeah,…	*Seeing a change/Identifying benefits for self/Calmness, peacefulness, less driven, slowed down* *Becoming kinder to self/Stopping pushing self so hard, allowing self to be rather than do* *Seeing a change/Identifying benefits for self/Changed, clearer priorities, purpose in life* *Becoming kinder to self/Looking after myself better, making friends with my body* *Sudden unexpected change in health, difficult to regain* *Trying to come to terms with change in identity – person with disability, LTC* *Getting used to symptoms, adjusting, odd what I accept as normal* *Impact on life and activities/Confidence* *Impact on life and activities/Functioning, incapacitated, debilitated* *(31/8/12)*

As I identified the main areas of experience, I also quickly started to differentiate the different dimensions of those experiences and how they interrelated, which led to the creation of provisional categories representing higher-level conceptualisations of aspects of the data. For example, Figure 5.6 shows a group of early codes relating to identity, with additional information clarifying the different ways it had been discussed.

Figure 5.6 Section of coding re 'identity'

- Identity - I am not my thoughts
- Identity - I'm just a human being
- Identity - letting go of beliefs and thoughts about self
- Identity - letting go of old identity and making new life
- Identity - not identifying self with illness - part of me, not whole
- Identity - owning identity as person with LTC
- Identity not affected cos symptoms not always there
- Identity - having LTC easier with age, normalised by others' illnesses   *(19/1/12)*

In reviewing this coding at a later stage, material from the first six codes was restructured and located within other categories, some of which are shown in Figure 5.7. I also realised that the last two codes (and other material) were not directly relevant to the analysis. These were therefore located in a broad *'Context: Living with a LTC'* category as background information.

Figure 5.7 Location of 'identity' theme within coding

Seeing self differently, seeing illness differently:
- Changed sense of identity - acknowledging illness but not identifying with it
- Changed sense of identity - realising I am not my thoughts

Letting go, stopping struggling:
- Letting go of old identity, beliefs about self, external labels   *(30/8/12)*

These two categories were 'relocated' a number of times as the overall coding structure continued to evolve, ultimately becoming part of a category within the higher-level theme *'Getting a new perspective'*. For some parts of the coding, this process was complex and lengthy, reflecting my uncertainty about the relationships between different aspects of the data. Other parts quickly seemed to take shape, and remained almost unchanged throughout the process. For example *'Feeling equipped to cope'* was identified very early as key theme and was retained in the final analysis, although some categories within it changed.

During the early stages of coding, many new codes were created from each interview, but towards the end of the first interviews most data could be coded to existing nodes (Richards, 2009). This diminishing need for new codes provided one indication that saturation was being achieved. Memos were used to explore and refine the developing coding structure, an example of which is shown in Figure 5.8. This phase of the analysis seemed to correspond to Charmaz's focused or selective coding stage (2001, 2006), whereby certain codes are identified as having more *"carrying capacity"* (Charmaz, 2006, p139) or *"analytical momentum"* (Richards, 2009, p111), and therefore become 'centres of gravity' around which other codes cluster. This reflected Charmaz's concept of 'clustering' (2006) which, as noted in 5.6.3.2, I found more helpful than viewing codes in a hierarchical structure.

Figure 5.8 Memo exploring coding structure

Working on codes around gaining, regaining control (24/2/12):

Just trying to pull these into some sort of shape. This idea about control is a big one, it comes up a lot and seems to be one of the key outcomes of the process for people. It, like all the other ideas, has a number of different aspects, which I am trying to tease out.

- there is a sense of having **choice** *about things - how to act, how to think. This brings more freedom. So things are not on automatic. Becoming aware of having a choice over things is at the core of this I think, and is an important thing for a number of people.*

ctd…

…ctd

*- linked to this is the sense of being able to **respond differently** to situations. This I guess comes about because of having the choice, which in turn comes from awareness. This includes being able to change behaviour I think, so have merged stuff to do with that into here. It is linked in with the idea of responding rather than reacting, which in turn is joined up with some of the codes around space at the moment - intercepting reaction. Is this the same? It also links with the whole stuff about stopping trains of thought which I am not sure is the same.*

*- another aspect is around **managing/controlling thoughts and feelings**. Again am not sure if this is really different to the previous point. The core of it is about people feeling they can manage, respond to difficult thoughts or feelings in a better way, so maybe need to add the difficult - done that. Of course, the thoughts and feelings are linked to experiences and situations, but I will leave it as separate for now.*

*- next one is around being able to **do more to help self**: different to the above, but links into other sets of codes about feeling equipped to cope. Will move stuff into equipped codes where possible I think and see if there is any other ideas left after that.*

It also links in with the 'opposite' theme around letting go - see other memos on this.

The term 'selective coding' seemed to most accurately reflect what was happening in the coding process at this stage, as it conveyed the sense of *existing* codes being selected to carry forward and structure the analysis rather than new ones being created for this purpose (Charmaz, 2001). This was reflected in the fact that the titles of many existing codes often did not change substantially, but their ordering and organisation became more refined and structured, with many codes being subsumed within others as the analysis progressed and others providing the names for the higher-level categories and themes. The memo extract in Figure 5.9 illustrates this process.

Figure 5.9 Memo discussing refinement of coding structure

*Making it my own - this is the overarching category at the moment into which everything fits around this - combining a few ideas here **16/3/12***

There are a number of aspects to this idea of making it my own, but it is a key to people using it successfully it seems, and it implies a responsive, aware, but also kind relationship to experience. Here's something I wrote earlier on this!:

23/12/11

Reviewing a bunch of codes relating to adapting tools to own needs and situation, which seem to contain a couple of themes within them:

*One is about **'making it my own'**, which I think would be quite a good overarching theme to develop – contains quite a lot of elements about selecting which meditations to use, and how often, and in what circumstances. Also contains stuff around not necessarily 'following the rules' in relation to how the things are taught.   This links in with memo about balancing rules with own needs. This one seems to be working out well – happy with this, and it is definitely a key part of how people talk about working with the stuff.*

The creation of a coding structure identifying the key dimensions of the data enabled the development of a preliminary model of the mindfulness experience, using NVivo's modelling function. This model, shown in Appendix I, was discussed and refined during the second interviews.

5.6.5.2   Second interviews

Due to a period of personal ill-health at the end of data collection, coding and analysis were suspended for five months. Returning to and familiarising myself with the data was challenging, but provided an opportunity to review it with more distance and with the additional experience of having undertaken the mindfulness training myself, as described in 9.2.2. To see whether these experiences led me to identify any new dimensions in the data, I intentionally began coding the second interviews without reviewing previous memos. It soon became clear that this coding strongly corresponded with my previous thinking, and at this stage I comprehensively reviewed the existing memos, combining those covering similar areas.

As the analysis of the second interviews continued, the coding structure was added to and refined, existing memos were developed and new memos were also written. As noted in 5.6.1, there was a high level of consistency between the data collected in the two interviews. This was reflected in the fact that relatively few additional codes needed to be created in order to integrate the second interview data into the existing coding. Some of these additional codes were significant, however. For instance, *'focusing on process rather than outcome'* was only identified clearly during this stage, leading to the creation of a new code which subsequently became a discrete category. Most of the work during this phase focused on identification of focused/selective codes, reflecting the more analytical exploration of the data. As part of this process, after coding a few interviews, I returned to the metaphor of an unwanted journey and explored its potential relevance in more depth, as will now be discussed.

5.6.5.3   Identifying a metaphor for the analysis

Early in the data collection and analysis, I reflected on how the metaphor of an unwanted journey to an unfamiliar country seemed to capture something of the experience of developing and living with a LTC, as illustrated in Figure 5.10.

Figure 5.10 Initial reflections on journey metaphor

Living with a LTC is a 'one-way ticket', or at best the return date is unknown and cannot be controlled: the previous country is not accessible, or not reliably so – the timing and length of visits cannot be chosen or predicted. Instead, they find themselves living, at least some of the time, in an unfamiliar land, which may seem overwhelming, strange, confusing and unpleasant. It is an experience of profound change and loss on many levels, and it presents a variety of practical and emotional challenges. The person has to respond to the changes being experienced, to adapt, and they may choose to do this with a variety of strategies, some of which may be more 'successful' than others. This experience seems to reflect what many people may go through who are obliged, for whatever reason, to move to a foreign country or unfamiliar environment.   (Undated memo)

At this early stage however, I was reluctant to impose the metaphor on the data, as I was aware that other themes and interpretations may emerge as coding progressed. As Figure 5.11 illustrates, I was also conscious the illness experience contained other dimensions:

Figure 5.11 Extract from memo 'Journey, migration image'

> *But in this case you are kind of a refugee within your own country, and you may look like the people around you so they don't obviously see that you are different. Parallels with sexuality, religion possibly, any invisible difference that defines you in some way as different and that is potentially negatively perceived – both by the wider group and by the individual (partly as a result of internalising the external perceptions). This to me is the closest analogy because it has the element of forced removal, then the choices about how much to try and hold on to the old ways/deny the change, also the confusion of not knowing how to describe what is happening to you. Also the potential to learn a new way of being, of coming to value yourself and not force yourself to fit something you don't anymore.*   *(11/3/13)*

I was also aware that some people's experience of living with a LTC was a lifetime one, with no or only very distant memories of a previous 'country'. Whilst recognising that this brought different dimensions to the experience, the metaphor still seemed potentially appropriate. The illness or condition may still be unwanted, creating a sense of 'exile' and struggling to find a way to live in a world that operates according to norms that do not match one's own experience. Although the unwanted journey metaphor was not then a 'perfect fit' for the illness experience, it contained many elements which I considered accurately captured the essence of participants' accounts and resonated with my own experience. Following a review of the memos I had written around this topic, and of the overall coding structure, I therefore decided to use this metaphor as the basis for shaping the findings from the analysis. This resulted in the coding structure being significantly reorganised around a number of key themes named to correspond with various aspects of the journey. Some of these themes already existed and some were new headings, as the memo extract in Figure 5.12 explores.

Figure 5.12 Memo extract discussing restructuring coding around journey metaphor

> *There's this sense of **starting from where you are** – that you have to begin by acknowledging where it is you have arrived. This is where being in the present moment and acceptance fit in, I think.*
>
> *Then there's something about **getting familiar with the territory** – this is where the seeing things clearly fits, the awareness, the moving towards difficulty and seeking the pleasant. These are all aspects of becoming familiar with your actual experience.*
>
> *There's also the **feeling equipped to cope** – so that's having a set of tools that can help you with this process – they both help you to get familiar with the territory and build confidence that you can cope with it (this is one of those many circular, self-reinforcing loops – if you feel more able to cope then you can become more willing to explore, and if you find you can do this then you feel more able to cope…). I think the sense of connection and support fits in here too - it's another part of feeling able to cope, better resourced.*
>
>   *ctd….*

….ctd

So, then we've got something around knowing what to do, which is where all the stuff about appropriate action comes in. I don't think knowing what to do is a powerful enough phrase to capture this. If we go back to the journey image, what is it? It's being able to navigate a route that works for you – both short term and longer term. Finding a way that works for you? **Finding your way?** *This links in quite nicely with the idea of making it your own, and expresses something about the individuality of what people do. It also expresses something about finding your way with your own illness, living with it. So there is finding your way with mindfulness, and finding your way with your illness....*

(11/3/13)

The ease with which it was possible to do this restructuring reassured me that this structure was not being 'forced' onto the existing coding but was consistent with it. This was also confirmed as coding of the second interviews continued, and most material readily fitted into or refined this new structure.

Although initially the themes had seemed to be linked in a simple linear flow, it became clear by this stage that the relationships were more complex and multi-directional, creating a number of self-reinforcing 'loops'. These 'loops' formed an important aspect of the experience of practising mindfulness for most participants. This recognition led to development of the preliminary model of the themes and relationships in Figure 5.13.

Figure 5.13 Early model of key themes and relationships
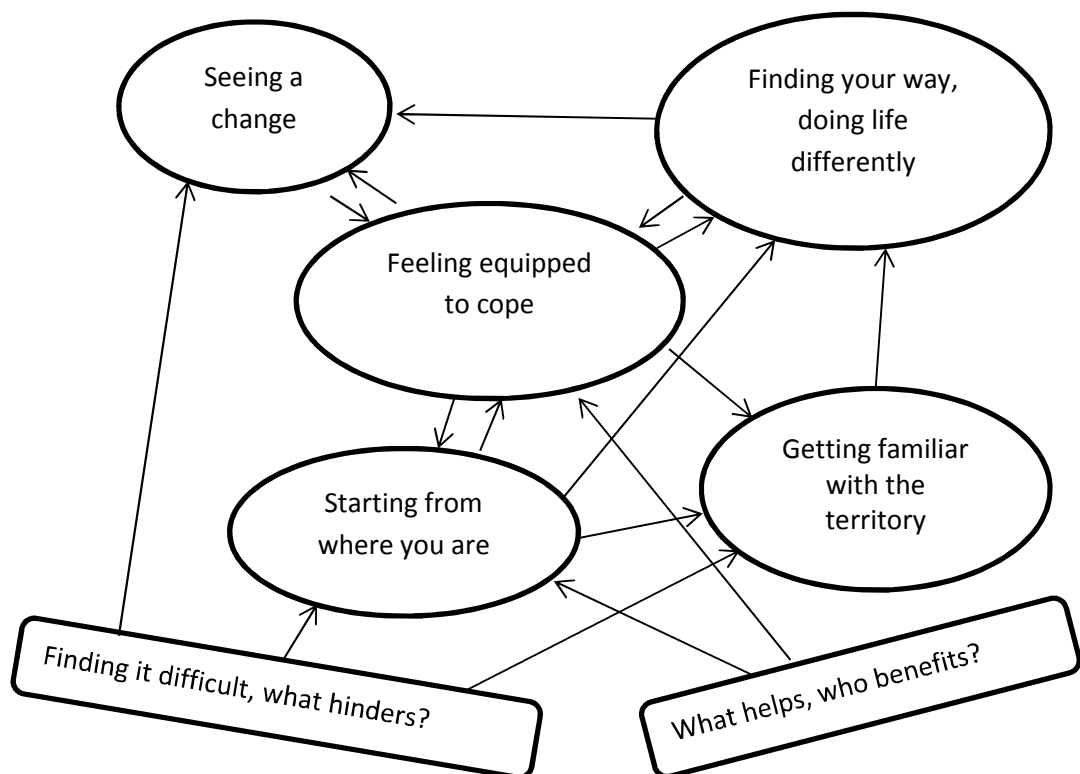
5.6.5.4   Graduates' focus group

As outlined in 5.6.1, analysis of the graduates' focus group data was integrated with the interview data. Given the high level of common experience between interview and focus group participants, most data reinforced the existing coding structure, with further refinements being made to the existing coding structure to reflect additional dimensions of experience. Participants often also used similar language, drawing on images and terms used within Breathworks' training.   The focus group explored a number of particular aspects of the analysis that needed further development, particularly around the ongoing use and practice of mindfulness.   It was notable that the experience within the group was predominantly one of having integrated mindfulness into life and changing how they viewed their condition, but not necessarily of continuing to practise formal meditation, or at least not on a regular basis. This dimension of experience was less well represented in the interview data, and the clearer identification of these contrasting approaches to mindfulness practice prompted some small amendments to the coding and subsequent discussion of this topic in the trainers' focus group.

5.6.5.5   Refining the coding structure: developing a coding frame

Having completed coding of the graduates' focus group, I reviewed the coding structure as a whole and identified areas where categories were not fully differentiated. This indicated that the analysis was still incomplete, and a number of strategies were used to progress this, particularly the introduction of a coding frame.   Each theme, category and sub-category was identified and its focus and contents briefly described, including how it related to or differed from other themes/categories. An extract is shown in Figure 5.14.

Figure 5.14 Extract from coding frame

Category	Sub-category	*Comments*
Making it my own, patterns of practice	Choices - selecting what works best for me, using what I need from the toolbox, different things for different purposes	*Identifying that some things are more useful than others – some get dropped entirely or only used occasionally. Also how people select different meditations to meet different needs, sometimes on a daily basis. These comments all relate to Breathworks meditations. This also includes comments relating to use of the CDs, which varies greatly.*
	Choices – integrating Breathworks meditations with other practices, support, medication, CBT etc.	*Many people describe combining the Breathworks meditations with a whole range of other tools, including other meditations from elsewhere, yoga, reiki etc, but also with other forms of support such as CBT, medication. Seeing Breathworks as part of a bigger package.*
	Choices – finding other practices more helpful, especially shorter, more active ones – Breathworks a springboard to these	*Some people no longer use the Breathworks meditations but have found other things that work better for them, perhaps as a result of attending the course. This particularly identifies that some people seem to need something more active/physical or something shorter – this may relate to certain personality types or conditions e.g. anxiety?*

The coding frame, accompanied by memo-ing, helped to clearly define the remaining elements of the coding structure. This led to some changes in the major themes, and a revision of the relationships between the themes, as shown in Figure 5.15.

Figure 5.15 Revised model of key themes and relationships
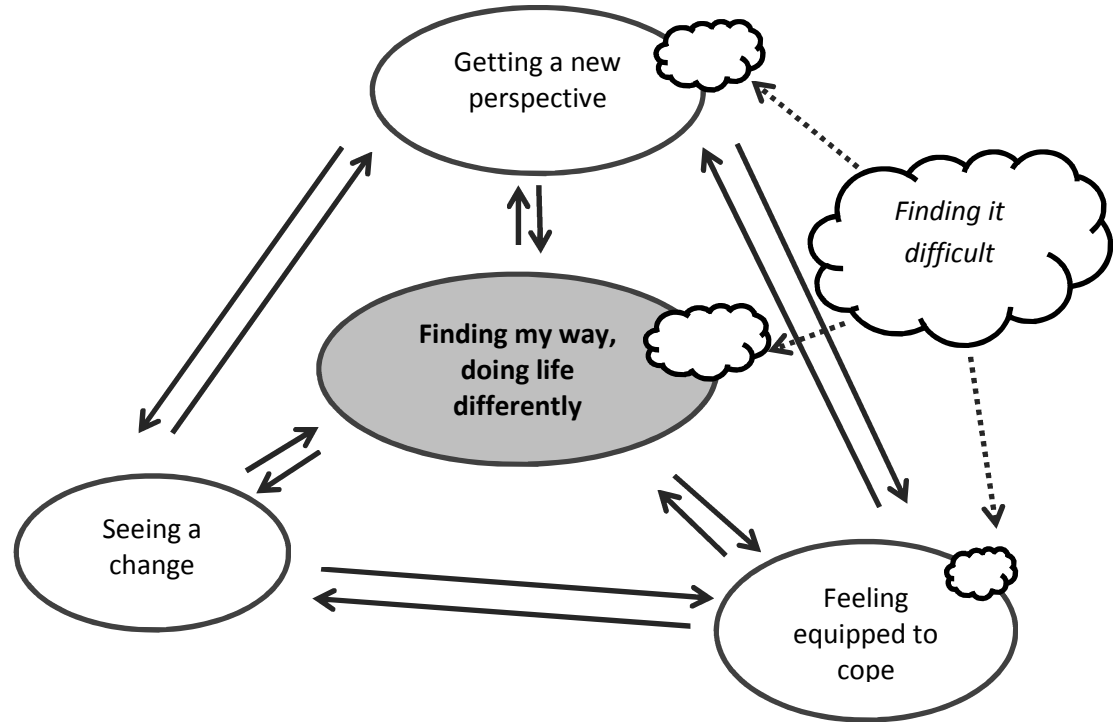
5.6.5.6   Trainers' focus group

Following completion of the previous stages, data from the trainers' focus group were analysed.   As with the graduates' focus group, the trainers explored a number of specific questions in order to refine and develop particular aspects of the analysis. In addition to their own experiences, the trainers offered their observations on the many other participants they had trained, which provided greater depth and breadth of understanding in certain areas. In particular, this related to identifying factors affecting people's ability to benefit from mindfulness practice, and exploring the different ways that people engage with the various aspects of mindfulness and meditation. As a result of this discussion, I restructured some elements of the coding frame; an example is shown in Figure 5.16, with red text indicating new material.

The trainers were also able to bring their understanding of the conceptual basis of the Breathworks programme and the relationship between its different elements, which enabled a deeper exploration of how mindfulness practices were adapted to meet the needs of people with LTC, and the particular role of meditation.   Although not always directly relevant to the research question, this provided important contextual information and also led to some small refinements to the coding describing patterns of practice.

Unsurprisingly, the trainers' personal experiences of mindfulness to a considerable extent mirrored those described by the graduates, and this data could mostly readily be assigned to existing codes. An additional, unanticipated and distinctive feature of the group was how the participants' behaviour provided a vivid demonstration of 'mindfulness in action'.

Figure 5.16 Coding frame extract showing revision from trainers' focus group analysis

Category	Sub-category	Comments
Applicability of course, mindfulness to different conditions, degrees of suffering (NEW)	*Explores different aspects of the question of who benefits and whether illness affects this. Pulls in some existing material from other places and adds some new in order to bring more of a focus around this question.*	
	Most seem to benefit to some degree, with a range of conditions (moved from 'Seeing a change/patterns of change')	*Observations from participants and trainers about the range of people that the course seemed to help. Also includes comments about the degree of benefit varying between people. Observations re drop-outs now in separate category.*
	Illness, condition, high levels of distress, stress or anxiety can make participation and practice difficult or unhelpful, access can be a problem (moved from 'Taking it on/finding it difficult')	*Illness – physical or mental - can directly affect people's ability to attend the course, or to engage with practices during and afterwards. Can be practical or emotional e.g. distracted, anxious, depressed or in a vulnerable emotional state. Comments about how people work with this, knowing when not to push, are in adapting practices to own needs and situation. Also acknowledges that there are external obstacles as a result of how Breathworks is set up that add extra barriers.*
	Finding mindfulness helpful even when suffering extreme physical or mental pain, distress (NEW)	*Trainers observations/experience of how some people in extreme pain/suffering appear able to benefit, offering another perspective on observation that some levels of suffering are too much to be mindful of.*

This experience is explored in detail in 8.4b.1, and confirmed and provided a clear example of a number of the themes identified in the data. This experience highlighted the distinctive type of data that focus groups can produce by revealing group interactions and culture, as explored in 5.4.2. Although this information formed an essential part of the data generated by the group, it was much more difficult to reduce it to individual codes within the existing structure. To ensure this dimension of the data was retained, detailed field notes and reflections were written. The experience was further discussed in supervision; this highlighted the significance and distinctiveness of the trainers' behaviour, as my supervisors could compare it with their knowledge of a wider range of focus groups.

5.6.5.7 Completing the analysis: identifying a core process and refining the themes

Following analysis of the trainers' group, I considered my coding structure was clear and coherent, with each theme and category adding a distinctive contribution to the whole, and the complex relationships between them being thoroughly explored. At the same

time, I recognised that this structure was only one possible interpretation, and that it would always remain provisional and open to refinement. This became apparent when the process of writing up the findings prompted yet further refinements to the analysis. This reflects Dey's (1993) observations that the process of writing forms a part of the analysis, stimulating the creation of a clear, coherent and grounded account *"that makes sense in itself and makes sense of the data" (Dey, 1993, p237).*

Writing up the analysis also led to the identification of an overarching theme of '*Starting where I am'.* This term was identified early in the analysis, as can be seen in Figures 5.12 and 5.13, and was variously located within the coding structure. On further reflection however, I considered it encapsulated the essence of the experience of practising mindfulness and living with a LTC, as Figure 5.17 illustrates.

Figure 5.17 Extract from 'Starting where you are' memo

There's a phrase, "If I was trying to get there, I wouldn't start from where you are", which is often used jokingly when somebody is […] trying to reach a particular destination when it's complicated, non-ideal, difficult to do.

This takes me back to the whole notion of seeing the chronic illness experience – or the coming to terms with it – as a journey …. I'm not totally clear what I think the destination is in this journey; it's something about being able to live life in a satisfactory way, which is something everybody wants to do regardless of their health but it's harder to do if you have some chronic illness affecting the picture. So, in this sense, the analogy to the "not starting from where you are" is if "I was trying to live a satisfactory life, I wouldn't start with a chronic illness". It's acknowledging that it makes things difficult, there are more obstacles on the way [….]

So the idea that you would actually start from where you are to me conveys something about accepting that this is where you are starting from, that you have accepted that and are starting your journey from that place.   *(1/3/13)*

Within the analysis, I decided '*Starting where I am'* therefore represented what is variously termed a central or core category (Corbin and Strauss, 2008, Birks and Mills, 2011) or basic social process (Glaser and Strauss, 1967, Charmaz, 2006). This is defined by Strauss and Corbin as *"consist[ing] of all the products of analysis condensed into a few words that seem to explain what 'this research is all about'"* (1998, p146). Recognising Charmaz's emphasis on retaining dynamism in the data, and GT's aim to identify process, I termed this the 'core process' in the analysis.

Identifying the core process led to some further and final restructuring of my model of the mindfulness experience, enabling greater theoretical integration of the themes and categories within the analysis. The resulting model more fully incorporated the core process and clarified the relationships between the other themes within it. One key consequence of this process was a differentiation between 'key themes' and 'supporting themes', based on their centrality to the core process. The final version of the themes and relationships is shown in Figure 7.1, where it is discussed as part of the findings.

5.6.6 Reflections on the process of coding and analysis

In the early stages, I felt there was alarmingly little 'outside' input into my analysis, and I was very conscious of how much my own ideas and interpretations were shaping the structure of the coding, and wanted someone else to 'check' it was 'right'(!). However, I realised this concern arose from my lack of confidence, and was not consistent with my critical realist perspective of there being no 'right' interpretation. These concerns receded as data collection progressed and the analysis gathered shape and momentum.

I had initially expected that there would be distinct stages to the analysis, moving in a linear fashion from open coding to selective/focused coding. In reality, I found things progressed in a much less 'tidy' fashion, with the two stages happening repeatedly and in parallel much of the time. I was initially concerned about this, but was reassured by Charmaz's (2001) description of the cyclical nature of the GT coding process, and with hindsight I can see this was inevitable. Data collection took place over a long period of time, and the analysis developed and took shape as this progressed. As a result, new data were being coded, primarily using open coding, at the same time as existing coding was being developed and refined through a process of more focused coding.

It took some time for me to realise I had identified a core process. As Charmaz does not emphasise this aspect of the GT process, I had not assumed I would necessarily find a central category (Charmaz, 2006), and it was something of a revelation when during the writing up, it suddenly 'clicked' that this had already happened. Corbin and Strauss's description of this process seemed to resonate with this experience: *"by the time this point in a study is reached, the integrative story is in him or her. It just needs to be drawn out."* (2008, p106). It was through the process of writing and reflection that I was able to 'draw out' what I had identified and recognise where it fitted within the analysis.

5.7   Chapter summary

The chapter has identified and discussed the methods used to carry out this research. The process of recruitment was outlined, including details of the sample from which participants were drawn. The different stages of data collection were explained, detailing the rationale and process of two-stage interviews, diaries and focus groups.   Ethical considerations were then explored and addressed. Finally an account of the strategy and process of analysis was provided to show how the key themes, categories and core process were identified. The next chapters present the study findings. Participant numbers and characteristics are provided in chapter 6, followed by two chapters presenting the findings from the analysis. Chapter 7 forms the core of this, and is based on data from the interviews and the graduates' focus group. Analysis of the trainers' focus group refines these findings in Chapter 8.

Chapter 6
Participant numbers and characteristics

Sandelowski notes that "the task of the qualitative researcher is to establish the position of all subjects in relation to the group of which they are members and the meaning of their slices of life" (1986, p32). To fulfil this recommendation, this chapter provides details of the research participants to establish the context for the findings in the following chapters. It begins by presenting information about the flow of participants through the study, and then identifies and discusses their socio-demographic characteristics.

6.1   Flow of participants

As described in 5.2.3.2, recruitment took place in a number of stages. Numbers and response rates for each stage are shown in Figure 6.1.

Figure 6.1 Sampling frame and respondent numbers

	Number approached	Number responding	% response rate
Centre L	72	16	22
Centre B	14	2	14
Breathworks trainers	46	9	20
Centre M	333	32	14
Breathworks founders	3	2	67
TOTALS	**468**	**61**	**27.4**

The lower response rate from Centre M may have resulted from the targeted recruitment strategy used at this stage. The programme had also been running much longer there, increasing the likelihood of people having lost interest or changed their circumstances. The use of Freepost reply envelopes may also have been off-putting: some of these were returned with added stamps, suggesting they may not have been universally understood to be cost-free.

Participants from each stage of recruitment were selected for inclusion in the different phases of the study. Figure 6.2 details of the flow of participants through the study.

Figure 6.2 Flow of participants through the study

```
┌─────────────────────────────────────────────────────────────┐
│              Sent recruitment mailing n=368                  │
│ Breathworks graduates n=319 (Centres B = 14, L = 72, M = 233)│
│ Breathworks trainers n=46 (North West, East Midlands, Yorkshire)│
│ Breathworks founder trainers n=3                             │
└─────────────────────────────────────────────────────────────┘
                        │
                        │──────────────────►┌──────────────────────┐
                        │                   │ Did not respond n=306 │
                        ▼                   └──────────────────────┘
┌─────────────────────────────────────┐
│        Responded to mailing n=62     │
│ Graduates n=51 (B 2, L 16, M 33)     │
│ Trainers n=9                         │
│ Founders n=2                         │
└─────────────────────────────────────┘
                        │
                        │──────────────────►┌──────────────────────┐
                        │                   │ Declined n=5         │
                        ▼                   │ Graduates (L 4, M 1) │
┌─────────────────────────────────────┐    └──────────────────────┘
│ Agreed to participate and screened n=57 │
│ Graduates n=46 (B 2, L 12, M 32)     │
│ Trainers n=9                         │
│ Founders n=2                         │
└─────────────────────────────────────┘
                        │
                        │──────────────────►┌──────────────────────┐
                        │                   │ Did not meet inclusion│
                        │                   │ criteria n=0         │
                        │                   └──────────────────────┘
          ┌─────────────┴──────────────┐
          ▼                            ▼
┌────────────────────────┐   ┌────────────────────────┐
│ Invited to interview   │   │ Invited to focus groups │
│ n=27                   │   │ n=30                   │
│ Graduates n=26         │   │ Graduates (M) n=20     │
│ (B 2, L 11, M 13)      │   │ Trainers n=8           │
│ Trainers n=1           │   │ Founders n=2           │
└────────────────────────┘   └────────────────────────┘
```

Interview suspended n=1

Completed first interview n=26
Graduates n=25 (B 2, L 11, M 12)
Trainers n=1

Did not participate n=13
No response n=2
Unable to attend n=6
(5 graduates, 1 trainer)
Did not attend n=5
(5 graduates)

No second interview n=6
Unable to contact n=3
Withdrew n=2
No longer eligible n=1

Attended graduates' focus group n=7
(M7)

Attended trainers' focus group n=7
Trainers n=5
Founders n=2

Completed second interview n=20
Graduates n=19 (B 2, L 7, M 10)
Trainers n=1

Twenty seven first interviews were arranged, although one did not take place for reasons explained previously. Twenty people participated in second interviews. The remaining participants either could not be contacted or initially agreed to second interviews and then withdrew. One person who had not been practising mindfulness in the intervening time did not take part by mutual consent, it being agreed there would be no additional relevant data. Seven people attended each focus group. As there was no overlap between interview and focus group participants, this formed a total sample size of 41.

Socio-demographic information about the participants is now presented and discussed in relation to national statistics. Due to the nature of the focus groups, where less disclosure was invited, more limited information is provided regarding these participants.

6.2 Interview participants

Participants were predominantly Breathworks graduates, although overlapping inclusion criteria meant four were also either qualified as or training to become Breathworks trainers. One trainer who had a particular health experience was also purposively sampled for interview to explore this experience in depth.

Details of individuals' conditions, ages and extent of participation in the research are given in Figure 6.3; some information is deliberately non-specific to ensure anonymity. As discussed in 5.4.1.2, the interval between the two interviews varied considerably due to changes in the timetabling of data collection. Many participants described long and complex health histories, which led me to classify most (24, 89%) as having multi-morbidity as defined in 2.2.3. Determining multi-morbidity was complex due to difficulties in deciding what should be considered a separate condition. My decisions were based on how I understood participants to be describing their health: where a number of separate conditions were identified by name, this was classified as multi-morbidity; where all symptoms were ascribed to one condition, this was not. In addition, some participants identified past illnesses or fluctuating symptoms which were not 'active' at the time of the interview, but had affected them since undertaking the course. Where I considered this illness, or fear of its recurrence, was continuing to impact on participants, this was classified as multi-morbidity.

Demographic characteristics are presented in Figure 6.4. The large majority of participants were female, of white British origin and aged over 45. Approximately two-thirds identified some religious affiliation. Over 80% had post-A level qualifications. More than three-quarters of participants were either not working or working part-time due to ill-health. The low number in full-time work may have been a result of this group being unable to commit to taking part in the research alongside working and managing a LTC. From informal conversations with Breathworks staff, it was ascertained that data relating to gender, ethnicity, religion and education level was broadly representative of their usual course participants.

Figure 6.3 Interview participants' health conditions, age and involvement in interviews

Pseudo-nym	Condition(s)	Age	Interval between interviews (months)
Barbara	Musculoskeletal, diabetes, anxiety, cancer	66+	n/a
Clive	Musculoskeletal, diabetes, depression, cardiac, asthma, possible neurological (physical effects)	56-65	9.5
Des	Neurological (physical and cognitive effects), stroke	56-65	n/a
Gloria	Neurological (physical and cognitive effects), diabetes, stroke, trauma/grief, depression	56-65	4.5
Hannah	Bipolar depression (long-term), musculoskeletal	56-65	6.5
Helen	Chronic pain, depression	26-35	9
Holly	Complex digestive problems, chronic fatigue symptoms	36-45	5.5
Jeannette	Progressive neurological condition (primarily physical effects), vertigo	56-65	9
Joanne	Thyroid function, ME/CFS, IBS, anxiety	56-65	7
John	Musculoskeletal, cancer, medication side-effects	36-45	5.5
Leah	Fibromyalgia, depression, asthma, diabetes, cancer scare	56-65	n/a
Louise	ME/CFS, fibromyalgia, traumatic medical incident, ?depression	56-65	6.5
Lydia	Cardiac, depression, memory, inflammatory pain condition	46-55	7.5
Maya	Anxiety, panic attacks, traumatic medical incident	56-65	9.5
Michael	Depression and anxiety (long term), intermittent pain	46-55	6
Michaela	ME/CFS, fibromyalgia, musculoskeletal, IBS, asthma, severe allergies	56-65	9
Nadia	Depression (long term), trauma/grief, musculoskeletal, fibromyalgia, ME/CFS, diabetes	46-55	5.5
Nell	Progressive neurological condition (primarily physical effects)	56-65	6.5
Robert	Chronic pain, depression	56-65	n/a
Rosalie	Musculoskeletal, ME/CFS, anxiety, panic attacks, trauma, depression, cancer	66+	5
Rowena	Complex neurological condition (cognitive & physical effects)	46-55	6.5
Sara	CFS/ME, fibromyalgia, depression	36-45	n/a
Shirley	ME/CFS, neurological (primarily cognitive effects), cancer (past history), musculoskeletal	66+	7.5
Sue	Cancer, related anxiety, chronic kidney/bladder problems, medication side-effects	56-65	n/a
Suzanne	Digestive problems (severe), neurological	46-55	n/a
Tania	ME/CFS, IBS, depression	36-45	4.5
Wendy	Neurological (long term, primarily physical effects), musculoskeletal, IBS, trauma, depression and anxiety	36-45	5

n/a: not applicable (did not participate in second interviews)

ME/CFS: myalgic encephalomyelitis/chronic fatigue syndrome

Figure 6.4 Interview participants' demographic characteristics

Characteristic		n (%)
Gender	Male	5 (19)
	Female	22 (81)
Ethnicity	White British	25 (92)
	White Other	1 (4)
	Mixed White/Black African	1 (4)
Age	Under 26	0
	26-35	1 (4)
	36-45	5 (19)
	46-55	5 (19)
	56-65	13 (48)
	66+	3 (11)
Religion	Buddhist	6 (22)
	Christian	7 (26)
	Jewish	2 (7)
	None	8 (30)
	Other	3 (11)
	Not stated	1 (4)
Education level	GCSE/Level 2	1 (4)
	A level/Level 3	4 (15)
	Higher post-A level vocational qualification	5 (19)
	Undergraduate degree	4 (15)
	Postgraduate degree/qualification	13 (48)
Employment status	Working full-time	4 (15)
	Working part-time due to ill-health	6 (22)
	Not working/retired due to ill-health	15 (56)
	Retired	2 (7)

Information regarding aspects of course attendance is presented in Figure 6.5. Over 80% had attended more than one year previously. The large majority were self-funding, with six having accessed the course via an NHS or other funded route. Most Breathworks courses have been run on a paying basis, but it is difficult to establish how closely the proportions in this sample reflect those of the whole sampling frame.

Before attending the course, approximately two-thirds of participants considered themselves to have little or no experience of meditation. Viewed another way however, these figures indicate that 70% of people had had some prior contact with meditation.

Figure 6.5 Interview participants' course attendance information

Characteristic		n (%)
Years since attending Breathworks	6 months-1 year	4 (15%)
	1-2 years	11 (41%)
	2-5 years	9 (33%)
	>5 years	3 (11%)
Funding for attendance	Self-funded	21 (78%)
	NHS/other funded	6 (22%)
Meditation experience prior to attendance	Never done any	8 (30%)
	A little experience	10 (37%)
	Some experience	6 (22%)
	Already regularly meditating	3 (11%)

6.2.1 Representativeness of sample

Compared to national statistics for people with LTC across England, participants' age distribution broadly reflected these figures (DH, 2012), chronic illness being more prevalent in older age groups. The oldest age group, i.e. over 65, was however under-represented. This is consistent with the MMBI research reviewed in chapter 3, and may result from additional barriers faced by this group, including poorer health, limited resources and less openness to an unfamiliar approach.

Most participants' education level, their ability to self-fund, and other subjective impressions indicated they were of higher social classes. As national figures indicate a higher prevalence and severity of many LTCs in lower social classes (DH, 2012), the sample was therefore strongly unrepresentative in this respect. Participants also differed in appearing to have a higher rate of multi-morbidity, which may account for the lower than national average in employment. These two figures, plus the proportion of women, were similarly high in a trial of a self-care support programme (Kennedy et al., 2007a), perhaps suggesting some people are more likely to engage in this kind of intervention.

Whilst the proportion of the sample indicating some religious affiliation is broadly similar to national census data, a disproportionately large number of participants identified as Buddhist. Additionally, other groups were under-represented; the absence of participants from a Muslim, Hindu or Sikh faith was particularly notable, these groups forming over 6% of the English population (ONS, 2011). At least some participants had become Buddhist as a result of attending Breathworks; it was not possible to establish whether people from this faith group had also been more attracted to the course because of its Buddhist links, although this seems likely.

6.3   Focus group participants

6.3.1   Graduates focus group

Seven people took part in this group, and their characteristics are presented in Figure 6.6.

Figure 6.6 Graduates' focus group participant characteristics[1]

Characteristic		n (%)
Gender	Female	6
	Male	1
Ethnicity	White British	7
Age	36-45	1
	46-55	1
	56-65	4
	66+	1
Religion	Buddhist	1
	Christian	3
	None	2
	Other	1
Education	Higher post A-level vocational qualification	2
	Undergraduate degree	2
	Postgraduate degree	1
	Not stated	2
Previous meditation experience	A little	2
	Some experience	2
	Already meditating regularly	3

Although the numbers are too small to draw significant conclusions, it can be seen that focus group participants shared many characteristics with the interview participants, being predominantly older white British women, although a greater proportion identified themselves as Christian. Where provided, education levels reflects the generally higher than average noted above. There seemed to be a greater level of prior meditation experience, with no-one identifying as never having meditated before attending Breathworks. However, this does not correspond with one person's account during the screening interviews of being unfamiliar with meditation, so it is possible the socio-demographic form was incorrectly completed. During informal conversation at the start of

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[1] Percentage figures are not given due to low total numbers

the group, participants noted attending the course varying lengths of time ago which seemed to broadly reflect those of the interview participants.

Participants were not asked to disclose their health conditions, although some chose to provide information during the discussion, and some details had been obtained whilst screening participants prior to attendance. Three identified themselves as having ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) and four had painful musculoskeletal conditions. A number had also experienced traumatic work-related incidents such as bullying.

6.3.2 Trainers' focus group

Seven people took part in this group, two of whom were founders. Their characteristics are presented in Figure 6.7.

Figure 6.7 Trainers' focus group participant characteristics[2]

Characteristic		n (%)
Gender	Female	5
	Male	2
Ethnicity	White British	6
	White Irish	1
Age	46-55	2
	56-65	5
Religion	Buddhist	6
	Other	1
Education	A level/Level 3	1
	Higher post A-level vocational qualification	1
	Undergraduate degree	3
	Postgraduate degree	2
Previous meditation experience	Never done any	1
	Some experience	1
	Already meditating regularly	5

Many of the characteristics of this group were similar to other participants, including gender, ethnicity and age. Educational level showed a broader spread than the other focus group, but was still generally high. Not surprisingly, given Breathworks' strong connection with the Triratna Buddhist Community, almost all participants indicated that they were Buddhists, whilst the remaining participant ticked both Buddhist and Christian affiliations. Again, probably unsurprisingly, most participants had a regular meditation practice prior to

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[2] Percentage figures not given due to low total numbers

contact with Breathworks, although one had never meditated before attending the course. As a requirement of being a trainer, all now regularly practised mindfulness meditation.

As part of the process of setting up this focus group, I had asked most participants to identify whether or not they considered themselves to have a LTC. I was therefore aware that at least five of the group were living with some level of long-term health problems, and one participant did not consider that they were.   Most trainers had begun their involvement with Breathworks through attending the 'Living Well with Pain and Illness' course and, having found it beneficial in managing their own LTCs, gone on to undertake trainer training. During the focus group it became apparent that, for some, their health conditions continued to impact very significantly on their lives.

6.4   Chapter summary

This chapter has presented the socio-demographic characteristics of the research participants, particularly the interview participants who form the primary source of data for this study, and their representativeness of the wider population with LTCs. Participants were predominantly female, white, over 45 and with a high educational level. Around two thirds identified some religious affiliation, and a similar proportion had had some prior contact with meditation. Most were not working, often as a result of their health condition. A wide range of physical and mental health conditions were represented, with the majority of participants classified as having multi-morbidity. Comparisons with national statistics for people with LTCs show a notably higher than average educational level, a lower number over 65, and apparently greater severity and complexity of illness in this sample. A higher than national average were Buddhists. The next two chapters discuss the experiences of these participants as recounted in the interviews and focus groups.

Chapter 7
Interview and graduates' focus group findings

7.1   Introduction

The findings in this chapter are based on data from the two-stage individual interviews and the graduates' focus group, together with correspondence from a participant whose interview was not completed, and memos written during data collection and analysis. As discussed in 5.6.1, data from the interviews and graduates' focus group were analysed concurrently, the participants forming a coherent whole. The analysis led me to select a metaphor of an unwanted journey to an unfamiliar place to represent participants' experience of living with a LTC. Based on this metaphor, I identified how practising mindfulness could be represented by a core process of '*Starting where I am'* and five linked themes. A complex pattern of relationships between the themes was identified, an overview of which is shown in Figure 7.1.

Figure 7.1 Relationships between key themes and core process
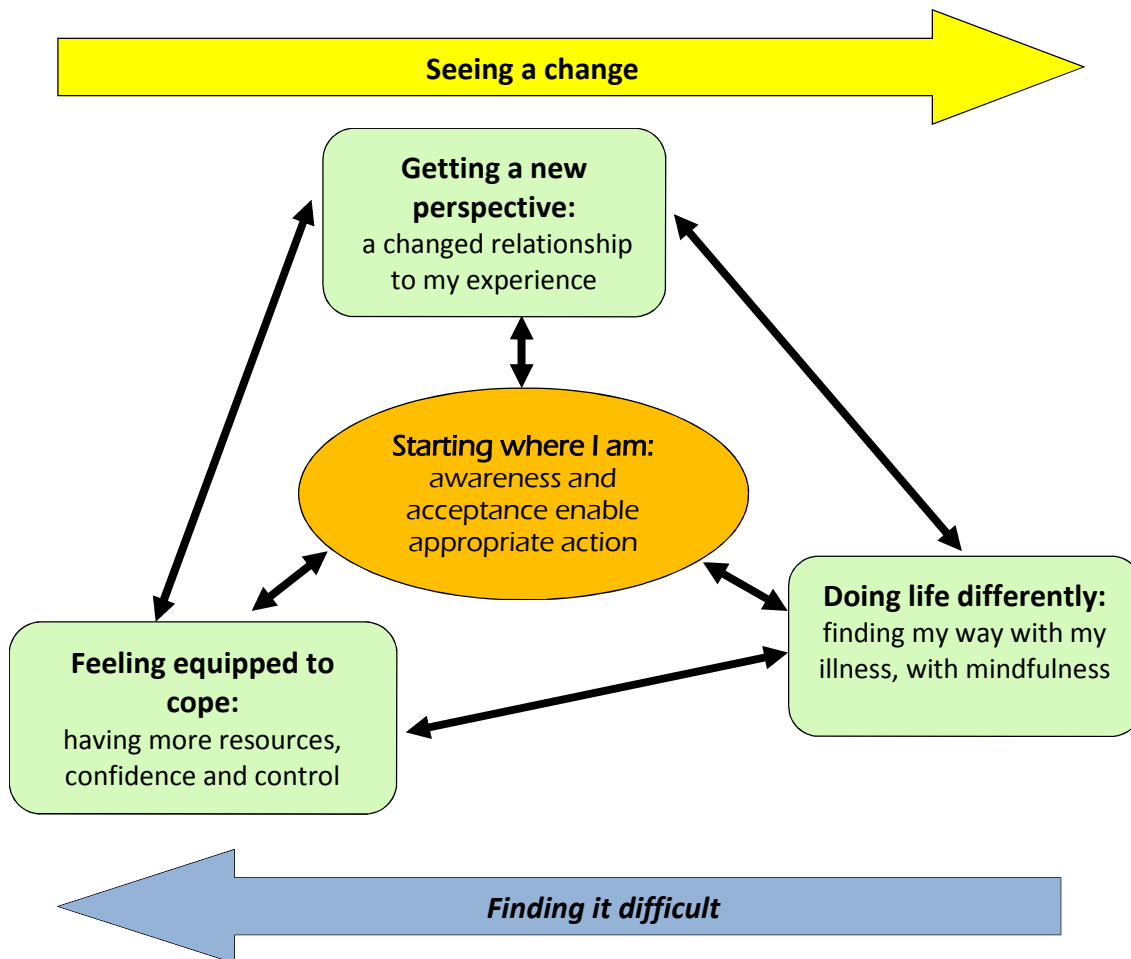
As discussed in 5.6.5.7, *'Starting where I am'* was seen to express the core process of how practising mindfulness affected people's experiences of living with a LTC. Three key themes: *Getting a new perspective, Feeling equipped to cope* and *Doing life differently*, directly inform this core process, and are central to its operation. Two supporting themes: *Seeing a change* and *Finding it difficult*, act as significant influences on the process, encouraging and inhibiting it respectively.

Each theme contains a number of sub-themes and categories, as shown in Figure 7.2, and will now be explored in detail, together with its relationship to the core process. To aid navigation, the categories and sub-categories relating to each theme are presented again at the start of that section. The exception to this is *Finding it difficult;* this theme is not discussed separately, but rather woven into the other themes and identified by particular categories indicated in italics*.*

Although the themes are presented here in a sequence, it is important to note that this does not represent a linear progression in experience, nor is it a 'one-off' process, but rather a set of linked aspects of experiences which may cycle round repeatedly, as is discussed further at the end of this chapter.

Illustrative quotes are included throughout, their origin designated by the participant's pseudonym followed by '1' for first interview data, '2' for second interview data and 'FG' for focus group data.

Figure 7.2 Themes, categories and sub-categories from the analysis

Theme	Category	Sub-categories
7.2 Getting a new perspective: a changed relationship to my experience	7.2.1 Moving closer to difficulty: facing up to and accepting how things are	7.2.1.1 Letting go of trying to fight, deny, solve the problem: accepting, facing reality 7.2.1.2 Allowing myself to acknowledge my difficult situation 7.2.1.3 Finding it possible to move on 7.2.1.4 *Finding it difficult: struggling to accept, move towards suffering*; balancing acceptance and change
	7.2.2 Stepping back, seeing the bigger picture	7.2.2.1 Appreciating what's good, looking for the positive 7.2.2.2 Keeping aware of the whole of my experience 7.2.2.3 Recognising that experience keeps changing
	7.2.3 Focusing on the present moment	7.2.3.1 Letting go of the past and future 7.2.3.2 Stopping trains of thought, catastrophising 7.2.3.3 Using mindfulness to distract myself from difficulty
	7.2.4 Finding a new sense of identity	7.2.4.1 Letting go of old identity and beliefs 7.2.4.2 Acknowledging but not identifying with my thoughts and illness
7.3 Feeling equipped to cope: having more resources, confidence & control	7.3.1 Having a range of accessible tools and skills I can use in everyday life	7.3.1.1 Having a structure, permission, something to do
	7.3.2 Having new ways to understand and talk about my experience	
	7.3.3 Feeling supported, connected, less isolated	*7.3.3.1 Finding it difficult: not feeling part of the group*
	7.3.4 Gaining confidence and competence in managing my condition	7.3.4.1 Seeing it's possible to live well with illness 7.3.4.2 Discovering, feeling confident mindfulness can help 7.3.4.3 Feeling competent, able to do something for myself
	7.3.5 Having more control and choice in my life, responding not reacting	
	7.3.6 Knowing and understanding myself better	

Theme	Category	Sub-categories	
7.4 **Doing life** **differently:** **finding my** **way with** **my illness,** **with** **mindfulness** 7.4a Finding my way with mindfulness	7.4a.1 Getting started	7.4a.1.1	Attitudes and perceptions help *or hinder*
		7.4a.1.2	Positive course experiences
		7.4a.1.3	*Finding it difficult: challenging course experiences*
	7.4a.2 Taking it on, keeping at it, finding ways to maintain practice	7.4a.2.1	Making time, making a commitment
		7.4a.2.2	Motivated by seeing a change
		7.4a.2.3	Making mindfulness a way of life, finding it becomes second nature
		7.4a.2.4	*Finding it difficult: struggling to establish and maintain practice*
		7.4a.2.5	Finding strategies to support practice
		7.4a.2.6	Research participation as a support to practice
	7.4a.3 Making it my own, developing patterns of practice	7.4a.3.1	Patterns: practising regularly or responding to need
		7.4a.3.2	Patterns: balancing formal and informal mindfulness practice
		7.4a.3.3	Patterns: practice changes over time
		7.4a.3.4	Choices: selecting what works best for me
		7.4a.3.5	Choices: integrating or replacing mindfulness with other tools
		7.4a.3.6	Choices: adapting practices to my own needs
7.4b Finding my way with my illness	7.4b.1 Aware of and responding accurately and appropriately to my needs	7.4b.1.1	Can monitor self, symptoms and respond more quickly, accurately
		7.4b.1.2	Can plan what to do to manage condition, meet needs
		7.4b.1.3	Can make informed choices and decisions about how to live life
		7.4b.1.4	Recognising I can do more, challenging myself, choosing to push my limits
		7.4b.1.5	Stopping sooner, not ignoring my needs, avoiding flare-ups
		7.4b.1.6	*Finding it difficult: Becoming aware of not being mindful*
	7.4b.2 Becoming kinder to myself	7.4b.2.1	Not judging myself as much, appreciating myself and what I can do
		7.4b.2.2	Looking after myself better, putting myself first
		7.4b.2.3	Being open with others about my condition and needs
		7.4b.2.4	*Finding it difficult: struggling to be kind to myself, put myself first*
		7.4b.2.5	Identifying the role of kindness
	7.4b.3 Focusing on process rather than outcomes		

Theme	Category	Sub-categories
7.5 Seeing a change	7.5.1 Identifying benefits for self	7.5.1.1 Seeing symptoms improve or stabilise 7.5.1.2 Coping better with difficult situations, including symptoms 7.5.1.3 Avoiding illness-related problems 7.5.1.4 Able to do more, managing energy better, having something to offer 7.5.1.5 Calmer, less driven, more relaxed 7.5.1.6 Clarity and focus 7.5.1.7 Positivity, optimism, confidence, rediscovering myself 7.5.1.8 Improved relationships, more connection with life and others 7.5.1.9 Better quality and balance of life, changed priorities 7.5.1.10 No negative outcomes
	7.5.2 Identifying benefits for others	7.5.2.1 Less worried about me, understand and know how to help 7.5.2.2 Improved relationships: I'm easier to be with, have more to offer 7.5.2.3 Developed or improved their own mindfulness practice
	7.5.3 Degrees and patterns of change	7.5.3.1 Degrees of change: it changed my life, it made no difference 7.5.3.2 Patterns of change: immediate benefit, cumulative effect

7.2 Getting a new perspective: a changed relationship to my experience

Most participants were living with chronic conditions they did not anticipate 'recovering' from, and some had a clear sense they were likely to see further deterioration in their health. In relation to the journey metaphor, they had arrived in a new country and had not been able to find a way back home, often despite many attempts. Many recounted their struggles with their illnesses, some of which were ongoing, and how these had affected their lives in almost entirely negative ways.   In these circumstances, a change in people's perspective on the new country became pivotal to how they experienced it, and their place within it.   Practising mindfulness facilitated this change, enabling them to relate to their illnesses and other aspects of their lives in new and helpful ways. This formed a key element of being able to *'start where they were'*, i.e. to engage with the new reality in a different way and change their relationship to their experience.

This new perspective enabled participants to look clearly at their difficulties, and accept that these were aspects of the new country they had arrived in. It also provided a means to get a broader perspective on their situation, to realise there was more than the unwanted and unattractive features that had sometimes dominated their view.   By focusing on the present moment they were able to see their difficulties in proportion, to let go of distress about a lost past and uncertain future, and come to terms with a new identity. These different aspects of *Getting a new perspective* will now be explored.

Figure 7.3 Getting a new perspective: categories and sub-categories

7.2.1 Moving towards difficulty: facing up to and accepting how things are
    7.2.1.1 Letting go of trying to fight, deny, solve the problem: accepting, facing reality
    7.2.1.2 Allowing myself to acknowledge my difficult situation
    7.2.1.3 Finding it possible to move on
    7.2.1.4 *Finding it difficult: struggling to accept and move towards suffering; balancing acceptance and change*

7.2.2 Stepping back, seeing the bigger picture
    7.2.2.1 Appreciating what's good, looking for the positive
    7.2.2.2 Keeping aware of the whole of my experience
    7.2.2.3 Recognising that experience keeps changing

7.2.3 Focusing on the present moment
    7.2.3.1 Letting go of the past and future
    7.2.3.2 Stopping trains of thought, catastrophising
    7.2.3.3 Using mindfulness to distract myself from difficulty

7.2.4 Finding a new sense of identity
    7.2.4.1 Letting go of old identity and beliefs
    7.2.4.2 Acknowledging but not identifying with my thoughts and illness

7.2.1 Moving towards difficulty: facing up to and accepting how things are

Mindfulness is fundamentally concerned with becoming aware of all aspects of present moment experience, including the difficult and painful ones. This is reflected within the Breathworks' programme which, as part of a process of developing increased awareness, encourages *"moving towards the unpleasant"* (Breathworks, 2009b, p17). In this context, this primarily relates to coming into closer contact with the reality of living with pain and illness:

> *So, umm, basically when I feel shit, or when I feel very panicky I have through the methodology really learnt to kind of turn towards it rather than kind of run from it, err (Michael1)*

A number of aspects of moving closer to difficulty were described by participants, many of which relate to the idea of acceptance. Paying attention to their experience of illness in a non-judgemental, accepting way provided many people with a helpful alternative to what they had previously been doing. However, moving closer to their suffering was also a very challenging experience, which some struggled to engage with in a beneficial way. This range of perspectives will now be explored.

7.2.1.1 Letting go of trying to fight, deny, solve the problem: accepting, facing reality

> *I was fighting, I was fighting everything. You know, I was trying to get answers. I was angry inside, I was frustrated, it's "why me, what have I done, and why am I tired? I don't want to be tired, I want to go out". [....] but sooner or later you've got to realise that you can't catch your shadow. And it was like, you know, to come back and this, this is what it created is, like, "well let's face up to it". (John1)*

Many participants echoed John's story, identifying how mindfulness had provided a radically different way of relating to their experience. People who had been struggling with their illness and putting their energy into seeking a resolution discovered a means to let go of that struggle and the emotions that went with it, including anger, self-blame and grief. They identified relief at finding a new way to relate to their experience, knowing their current strategies were not working but having been unable to find an alternative:

> JL: And if you had to sum up what change it made for you then, doing the course what would you say?
> Rowena: Oh it saved my life, I think it saved my life.
> JL: Right, literally?
> Rowena: Yes, literally, literally. The day I lay in that bed – oh I'm going to cry – I just realised that there was no point ranting and railing about it, that was… that's like the acceptance, that was what the situation was, like I either accept it and work within it and do whatever I could, because I knew that the pacing worked, or, I could carry on ranting and railing and just make myself even more and more ill. (Rowena1)

Although this was often a dramatic shift in perspective, some found it relatively easy to make, often commenting on how it 'made sense'. Tania felt *"total relief […] that there was something that I could go along with and that was right"* (Tania1), having previously

struggled to come to terms with ME and a number of significant losses in life resulting from it. This, for some, linked to the idea of 'readiness', which is explored further in 7.4a.1.1.

7.2.1.2   Allowing myself to acknowledge my difficult situation

A number of people remarked how moving towards difficulty provided an important opportunity to validate their experience of illness, which they had previously been denying or struggling to come to terms with.   It allowed them to recognise that they were *"dealing with something that was very difficult" (Helen 1)* which, for Wendy, was a change in a lifelong pattern:

> *…I met people who were in pain, who were encouraging me to acknowledge my pain, and that was quite refreshing, really. More refreshing because I don't do it, I don't do it naturally myself. (Wendy1)*

Helen's struggles seemed partly related to her 'diagnosis' of unexplained chronic pain, which did not offer a validating label for her experience. Both she and Wendy noted that mindfulness helped them counteract the tendency to think they were 'making up' their difficulties, and to acknowledge their experience as 'real'. For others, acknowledgement represented a move from denial to acceptance of their illness:

> *…there was a, a woman there who was having problems dealing with her condition, and I think by the end of the course she could actually say "Good grief, yes, I <u>have</u> got MS", which I nearly cried my eyes out, you know? (Nell1)*

This recognition and validation was an important step in supporting people to work differently with their illness, in particular reducing their tendency to push themselves to act as though it was not affecting them, which often created further problems. This change is explored further in 7.4b.1.5.

7.2.1.3   Finding it possible to move on

Acknowledgement and acceptance of the reality of their condition and difficulties of their situation acted as an important step in enabling many people to move on from the 'stuck' place they were in with their illness. It provided some with an important first step towards dealing with their condition more appropriately and accurately, as is explored in detail in 7.4b. It allowed energy and attention to be focused in new directions rather than blocking out what was happening, pursuing a cure, or in the emotional turmoil that many had experienced. Clive recounted losing the feeling of *"why me?"*, and moving to:

> *…why not me? […] there's lots of people out there that are a lot worse than me, so why me is a complete waste of time really. (Clive2)*

Sue recalled being able to manage the acute anxiety of waiting for and receiving a cancer diagnosis in a way that made a significant difference to her:

> *So, so, I wasn't <u>fighting</u>, ……, I wasn't saying "Oh I don't-, I don't want to feel anx-, oh no, this is awful, this is awful" , I'd just sort of acknowledge "Oh, I'm, feeling whatever". (Sue1)*

This ability to observe emotions in a non-judgemental way is fundamental to mindfulness, and applies equally to difficult thoughts and physical sensations. Kathy described initially

using mindfulness for her back pain, but more recently finding it helped her respond to the emotional pain of bereavement: *"well really just accepting my sadness and loss […] to just come back to where I am really" (Kathy, FG).*

Many participants identified how letting go of struggle had created a greater sense of control, choice and freedom in their lives – these ideas are explored further in 7.3.5. Although this process of acknowledgement and acceptance was pivotal, and led to significant positive change, for some it was also very challenging, as is now discussed.

7.2.1.4   Finding it difficult: struggling to accept and move towards suffering; balancing acceptance and change

For quite a number of participants, the experience of coming into closer contact with their suffering proved extremely distressing, as exemplified by Helen's account:

> *I found it very hard initially on the first course, [….] we did a body-scan and I found it such an extreme sort of meeting my pain in that way that I just spent the whole of the rest of the session crying I think (Helen1)*

Joanne observed feeling her ME/CFS limited planning so much that she was *"excruciatingly painfully in the moment all the time, and that moment's not a good place to be" (Joanne1)*, whilst Susanne, whose interview did not take place due to her distress about her condition, commented by text message that moving closer to her suffering was unbearable, and she did not therefore use mindfulness meditation:

> *When I'm really suffering like this and in difficult surroundings. I just can't meditate. You'd think it would help wouldn't you but it doesn't. All you can do to get through horrible procedures or endure hospital surroundings is go "into the zone" or use distraction techniques. (Susanne1)*

The difficulty involved in becoming more aware of suffering suggests why some people may not be able to engage with mindfulness; it also highlights the importance of learning to work skilfully with this awareness, which is explored further in 7.4a.3.6.

Given the challenges some people faced in 'moving towards difficulty', it was not surprising that the suggestion of acceptance of it also sometimes provoked significant difficulties. A number of participants described resistance to the idea, particularly at first, and the issue remained an on-going challenge for some. Rosalie observed how acceptance had required a change of focus from looking for *"something that was going to take it all away" (Rosalie1)*, a challenging shift in perspective. Others struggled with the perception that acceptance meant *"I have to love my pain" (Helen2)* or that they <u>wanted</u> to be in a particular situation:

> *I didn't want me brain haemorrhage […] I didn't want to be left with all me problems, [….], I had to finish work and I lost me job, cos I couldn't work, I didn't want that. I didn't want N to be ill, and I didn't want N to die, and I didn't want to be left living on me own, and I'd no control over any of it. (Gloria1)*

Gloria also found difficulty with the emphasis on focusing on the present moment, which seemed to contain only losses, compared to a happier past. However, her struggle led her

to greater appreciation of these concepts, at least partly as a result of seeing the benefits of practising mindfulness regularly. Other participants also described a journey with the idea of acceptance, and of gradually moving to a different perspective. This journey was sometimes apparent between the two interviews, most notably with Tania. In the first interview she emphasised that *"I wouldn't want to think that that this [illness] was it forever, because I don't know how I would come to terms with that" (Tania1)*, whereas four months later she reflected:

> *Cos I've got it and I live with it, and it's a thing that I think 'well if I was to get better', rather than 'when I'm alright' so I can cope with living, I can cope with it forever now, forever in fact… (Tania2)*

This illustrates the view expressed by a number of people of acceptance as an on-going process rather than a 'one-off' transition that could be completed. It also demonstrated participants' willingness to take on the challenges of mindfulness, discussed in 7.4a.2.

For some, the biggest obstacle to acceptance was its association with ideas of resignation, defeat and passivity. Acceptance was equated with relinquishing control or giving up belief in the possibility of change. From this perspective this was understandably a difficult thing to do: Sara recalled initially feeling *"…if there's no cure, I'm better off dead" (Sara1)*. The idea of making no further effort to improve their health problems was also not something they could contemplate:

> *…I still think if I was totally accepting of it then it wouldn't push me to try and change things for myself, and I think that's a good thing that. (Holly1)*

Given that participants were attending a course to help them change how they lived with their condition, and most had paid to be there, it is perhaps not surprising that this understanding of acceptance was unacceptable to them. People described negotiating a balance: accepting and acknowledging their circumstances but *"without giving up hope altogether" (Hannah1)*. They retained the possibility that their situation might improve and did what they could to this end but not *"striving to do the impossible" (Holly1)*. This illustrates a broader theme of gaining control and letting go, which is explored in 7.4b.3.

In a similar way, participants recognised the need to balance moving towards the difficult aspects of their experience with viewing them within a wider context and perspective. The next section explores how they saw mindfulness enabling this to happen.

7.2.2   Stepping back, seeing the bigger picture

Although facing and clearly seeing the difficulty of a situation is an important part of a journey, this can become an overwhelming experience. Perspective can be lost, with the negative aspects of the situation dominating the view and obscuring other aspects of it. This can then create further suffering and distress. It is therefore important to maintain a wider perspective. The process of mindfulness is one of consciously choosing to keep the *whole* of present moment experience in awareness; this includes difficult aspects which may have been blocked or denied, but also positive or pleasant aspects. In this section, I

explore various ways that participants described changing their perspective to take a step back from their illness and see it in a wider context.

7.2.2.1 Appreciating what's good, looking for the positive

Many people commented on how their experience of illness and difficulty could become the sole focus of attention, and of the need to be reminded of other, more pleasurable aspects of their experience. The Breathworks programme encourages participants to *"seek the pleasant"* (Breathworks, 2009b, p17): to use mindfulness to discover *"what is there in this to take joy from?" (Jeannette2)*. Many people commented on the value of this approach in helping to change their experience of their illness, such as Hannah's description of an episode of pain and depression:

Hannah:	… I was in a great deal of pain and feeling very miserable really
JL:	And you were using some of the mindfulness stuff at that point?
Hannah:	Without, sort of putting labels on it, yes, because to try and dilute the pain a bit, I sort of just try and focus, say on the birds or bird song that I could hear or anything like that (Hannah2)

Seeking out the positive aspects of experience provided a powerful balance to people's awareness of their difficulties, and mindfulness provided valuable tools to enable this. Participants learned to *"just look for something very, very small […] you can always find something nice" (Rosalie 1)* in their experience, which could help to change their perspective and lift their mood. Michaela recounted noticing and valuing aspects of her body which <u>did</u> work well, rather than solely focusing on the parts that caused her difficulty. She and others also recounted being able to recognise pleasant experiences that were an indirect result of their illness, in particular greater appreciation of their surroundings due to having to do things more slowly. More generally, participants emphasised how mindfulness enabled them to appreciate aspects of their everyday environment and life in new ways:

…it's like when you just sit and look at a flower and just really really look. It's taught me, the mindfulness stuff has taught me to really, really look at things, fully…, and properly and see their intrinsic worth. A flower, I mean I didn't used to realise that I could spend hours just looking at <u>one</u> flower and admiring <u>one</u> flower and its petals, it never would've occurred to me to do that… (Michaela1)

Participants noted making a conscious choice to approach their experience from this new perspective: *"if I do decide to do something I'm really going to enjoy it" (Louise1)*. Over time, this became a pattern of behaviour which helped people to cope with the difficulties of their illness, and with other challenges, such as Michael's account of spending time with his mother as she neared the end of her life:

….whereas with that little bit of mindfulness and that little bit of distance I'm taking it in a slightly more open and receptive way, you know, even if it's like the sadness of my current experience with my mum […] I can still experience that in a kind of sad but beautiful way as well, as it's t-, you know, it's, you know it goes deep with me but I can also sort of just, just about stay with a larger narrative of the beauty of her as she still is now, breathing, a breathing, sentient being. (Michael1)

This changed perspective, of being able to *"get more out of what you're doing <u>now</u>" (Clive1)*, contributed significantly to participants' sense of having a better quality of life, a theme explored further in 7.5.1.9.

7.2.2.2   Keeping aware of the whole of my experience

By acknowledging the difficult and seeking the pleasant, participants described being able to hold all of the aspects of their experience together, neither being overwhelmed by the difficulties nor blocking them out entirely. A concept taught within Breathworks *,"the bigger container"* (Breathworks, 2009b, p18) was sometimes mentioned in this context, suggesting the idea of seeing each particular experience within a wider perspective. In terms of the journey, this seems akin to being able to look around at the whole of the situation rather than narrowly focusing on one part of it. In this way, the difficulties become relatively smaller within the whole picture, and unexpected pleasant experiences become more possible. However, nothing is excluded:

> *… they talk about acknowledging the pain, but also acknowledging the pleasant, and I-, and both of them are important, so um-, and I liked that about it, it was not "I'm in pain, oh poor me", "I'm in pain, oh poor me, but… there's a nice cup of coffee here". (Wendy1)*
>
> *Yes it helped me open my eyes and my mind to myself […] and I just thought well okay this is life this is pain, this is where I am at, I'm not going anywhere, there is nothing else I can do about it, but I know there's good days, and when good days are here I take advantage of these good days. Even though I have bad days, during the bad days I still think about things I did in the good, when I had good days, to try and help make the bad days better (Lydia2)*

7.2.2.3   Recognising that experience keeps changing

Another element of seeing the bigger picture was locating difficult experience in a broader time perspective, and discovering that it actually constantly changed rather than being permanently and unremittingly bad. For some, this change of perspective reduced the impact and power of their present pain or distress and made it easier to bear. They were able to recognise that things could, and did, change:

> *So actually, …, even if, even if what's in the mind is really awful, the mind will move on from that (laughs) unless - you lock onto it. […] but if you just let it go, which is like we go in the-, actually if you watch your mind, the mind can go "Oh my god, this is really terrible, I could die", to …, to "Oh, goodness, I didn't get dog food!" (Sue1)*
>
> *…you know at the moment me chest's pretty sore and me, me knees are pretty sore and stuff but this afternoon they might be fine. So they hurt <u>now</u>, but, so, that's, you know, it might change […] So it in't all sufferin', I might be OK this aft' …, I might not be dizzy and sick this aft', so that gives you a sense of balance. (Clive1)*

Michaela recounted using mindfulness to remind herself of the temporary nature of an unpleasant medical procedure, and how this helped her to manage the situation:

> *…I got through it minute by moment by moment, and I breathed, it was difficult to do, I was going to do mindfulness of breathing but it was difficult, I was in such a funny position on the chair with my legs in the air it was difficult to do that properly, but it didn't matter because I talked myself mindfully through it 'all I have to do is get through this moment, this moment, and this moment'. And because I've done that I know I can do it next week as well. (Michaela2)*

Mindfully focusing on the present moment also brought participants benefits by taking them <u>away</u> from unhelpful thinking about the past and future, as will now be explored.

7.2.3   Focusing on the present moment

Participants identified a variety of other ways that being 'in the moment' helped them manage their illness. In particular it enabled them to redirect attention from distressing aspects of the past and future, or from unhelpful thinking patterns. The first two points below identify 'conventional' descriptions of these benefits, whilst the final point discusses accounts of using mindfulness as "a distraction", an apparent contradiction given that mindfulness is an attitude of awareness of the whole of experience.

7.2.3.1   Letting go of the past and future

One frequent aspect of participants' previous struggles with their illness was being drawn into focusing on the past or future. This often significantly added to their distress in various ways. Some described grief and regret for what was lost, or blame and anger – generally with themselves – for how things were now. They struggled to let go of the person they had been, or of hopes and plans they had had for the future. Looking forward often provoked fear and anxiety, both in relation to their illness and life in general. Whilst these reactions were inevitable and a necessary part of coming to terms with the profound changes in their lives, participants found they could also become overwhelming, as noted above. They identified how mindfulness, with its focus on the present moment, enabled them to come to a different relationship with these emotions:

> *To live in the present, not worrying about whether I'm gonna end up in a wheelchair, not, not grieving for the past when I was dancing, and running around… (Nell1)*

Through cultivating an acceptance of their experience, participants were more able to let go of thoughts about the past and future. Most commonly, people highlighted how this approach reduced their worry about both their immediate and longer term situation:

> *…there is some steps ahead of me, you know, if it turns out it is […] cancer, what stage, what treatments, there is things ahead of me, but what I'm trying to do at the moment, the way I'm looking at it is say 'well let's worry about that when I get there', what I've got to do now the first thing is, is get over the operation and get the stitches out. The next step is to say, 'okay, is it or isn't it, and if it is, what are we going to do?' (John1)*
>
>
> *…I would lay in bed at night and thinking 'what's my life going to be in another year or two?', I don't do that anymore, I don't do it about anything, I just live more in the now… (Kathy, FG)*

Illustrating the value of dealing only with what was happening at the time rather than what was to come, Clive succinctly observed,"*…you can't suffer a life-time of illness now…"* (Clive1). Others identified how putting less energy into thinking and planning ahead had reduced their stress levels and allowed them to enjoy life more. Increased awareness also enabled them to notice when they were starting to return to old patterns, and to pull themselves back into the present moment.

Participants also described letting go of looking back over what had happened and trying to find reasons, or feeling responsible for their illness:

> *…I'm trying to let go. Be easier on myself and other people, like I said, have less expectations, and less negative thoughts about the past, all the time blaming myself for things that I shouldn't have done and, you know, try to live for now (Sara1)*

They were more able to stop trying to return to their past activities, and come to terms with *"really accepting that I had a different life before this and this is another life" (Holly2).* As explored above, they could also appreciate the positive aspects of their new reality (7.2.2) and create a new identity for themselves (7.2.4). Similarly, participants were more able to accept the loss of the future they had hoped for, whether in terms of career, independence, good health or, in Michaela's case, having children:

> *… there's been lots of losses along the way, […] but the biggest one for me is the children… and it's something I've had to work really hard and I've found the mindfulness and the meditation extremely good with that actually… (Michaela1)*

Living in the moment had helped Michaela begin to let go of the jealousy, self-pity and failure which she had suffered. Others similarly noted being less angry or resentful, and more able to accept their situation with all its difficulties and to *"develop equanimity in the face of the uncertainties of [illness]" (Jeannette1).* As emphasised above however, this did not mean 'giving up', but letting go of things which were outside their control and focusing their energy on the present:

> *…so if I find myself worrying too much or if I find myself picking something over from the past I say "Well, you know, the past is the past, that's gone, and actually I may not even be recalling it that well", […], also with the future, you know it's not here is it? […] I'm much more able to live now, so I think that's been quite a big thing … (Sue1)*

7.2.3.2   Stopping trains of thought, catastrophising

One aspect of being more focused in the present moment, mentioned by almost everyone, was participants' ability to catastrophise less about their situation. This overlaps to some degree with the previous section but has a number of additional dimensions. Mindfulness enabled participants to pay close attention to was actually happening, and to clearly differentiate this from imagined 'worst case scenarios' and their associated emotions:

> *… you stop, think about what are you actually feeling. Not what do you think you are feeling? What are you really feeling? And there is a difference. (John2)*

Some described this experience using the Buddhist terminology of primary and secondary suffering, which, as explored in 2.3.1, recognises how the interpretation of and reaction to difficulty can add substantially to the suffering experienced:

> *…that really has to be one of my important ones because what it does, when you start to focus on primary pain, is reduce the fascination, whatever it might be, with secondary pain […] so I know that I've done something to this leg or whatever, right? By the time night time comes and I unwind, that pain isn't just here, it's throughout my body and so my experience of it could be, unaware, "Oh my God, I have got polymyalgia, I need steroids, I should be at the doctor's tomorrow, […] I'm feeling really low and I need antidepressants". […] "I give up, that's, that's the route, you're dead right Dr B (name of doctor), why have I been so stupid?" (Louise1)*

Louise noted that she was able instead to clarify where her pain originated from, what had contributed to it and what she needed to do to ease it. This enabled her both to relieve the pain and to regain a sense of control of the situation. Others similarly identified understanding what was happening more clearly, and recognising that although they were experiencing pain or other symptoms, these may not have the meaning they might ascribe to them: *"it's not pain that's panic like you are going to have a heart attack" (Kathy, FG)*. In some instances looking more closely also enabled people to realise that the situation *"wasn't as unpleasant as I thought" (Hannah1)*.

People described learning to manage their symptoms by mindfully watching and naming their experience in the moment. This enabled them to detach slightly from what was happening; to look <u>at</u> it rather than being immersed in it, and to see it as *"just an experience" (Michael1)* consisting of bodily sensations, thoughts and emotions. Some found this strategy particularly useful in situations of acute anxiety, where paying detailed attention to their experience provided a new clarity about their situation, which helped avoid being overwhelmed by it:

> *…this sort of ability to sit alongside what was happening rather than to be sort of caught in or consumed by what was happening was the most powerful thing I think. (Sue1)*

As noted above, participants also identified being less likely to project forward to future pain or difficulty, and not being drawn into catastrophising about the consequences of their illness for their lives, but instead focusing on what they were dealing with now:

> *…that stops your mind going off onto all these "what could be's" […] because they're not really important, because they don't exist, do they? What may be and what could be aren't anything, they're not real things, they're something your mind's making up, 'cause you can't tell the future. (Clive1)*

Another way participants 'stopped trains of thoughts' was by noticing and avoiding rumination which could trigger depression, a symptom identified by approximately half the participants. Mindfulness offered a means to more readily spot this pattern. It also provided tools for *"getting onto other tracks" (Hannah1)* by encouraging a focus on present moment experience, either through the meditations or increased awareness of surroundings and activities. This gave people more sense of choice and control, which is

explored in 7.3.5. Helen particularly identified the value of mindfulness in helping her let go of over-thinking, in comparison to CBT which she found had encouraged it.

A number of participants described how acceptance had helped them reduce 'victim' thinking in relation to their illness. This was part of a larger pattern of *"changing the stories we tell ourselves about the pain" (Michael1)* and thus reducing emotions such as self-pity, despair, anger and panic triggered by those stories. Although being in touch with the reality of their situation was challenging, participants found it could significantly reduce this 'secondary suffering':

> *I feel like now I just live with the illness which is mad, because you know that is so much easier, just to live with the illness instead of like everything else that comes with it…*
> *(Tania2)*

These changes in thinking patterns and consequent reduction in distress sometimes also impacted on participants' 'primary suffering'. Michaela found mindfulness provided *"a way to cut through the tendency to any vicious cycle [of pain and stress]" (Michaela1)*, and could reduce the duration or severity of episodes of illness. This experience was echoed in relation to a range of illnesses and other stressful situations. Being able to *"just step back a bit" (Maya2)* therefore made a significant difference to people's experience of their condition, as was explored in 7.2.2.

7.2.3.3   Using mindfulness to distract myself from difficulty

Although Breathworks encourage people to use mindfulness to change their perspective through choosing their focus of attention, this is distinguished from distraction or "blocking", where difficulties are deliberately avoided. This is a subtle distinction: the former strategy is distinguished by its retention of consciousness of difficulty, which may be lost in the latter. Distraction could therefore be seen as non-mindful, and was certainly viewed as an undesirable state by some participants. However, around a third of participants recounted the value of mindfulness tools, in particular the guided meditations, in distracting them from difficult physical or emotional states:

> *The nice thing about mindfulness is it takes your mind off other things, you know, it, it can be a really effective distracter (Barbara1)*

For a number of participants with anxiety, stress or depression, mindfulness offered an alternative focus which took their attention away from intrusive and unhelpful or distressing thoughts: *"just concentrating on what it is I'm actually doing rather on my mind flitting off somewhat else" (Hannah2)*. Others found mindfulness, including breath awareness, a valuable distraction from pain and depression, helping avoid rumination and giving "*another thing to focus on" (Nadia1)* when they were struggling. Holly recounted how the meditation *"just knocks off that loop thinking" (Holly2)* that she recognised as associated with a tired, stressed state, while Barbara, who suffered from anxiety, valued how this then helped her to get to sleep. A few people with severe pain recognised how the meditations provided a valuable tool to distract them; Lydia also noted how it gave her *"instruction on what to do and how to think" (Lydia2)*, enabling her to calm herself, which in itself eased the pain to a degree.

A few acknowledged the limitations of distraction, but recognised its value as a temporary strategy. Maya, who was exploring her ways of managing anxiety, reflected:

> *…what I tend to do is use escapism mechanisms and that's not good. Er, so I can't even use the mindfulness as an escapism in a way, except I can use it for a while to give me some strength to then face up to it. (Maya2)*

A similar point was made by Helen who observed that anything, including mindfulness, could be used as a distraction, and that this was sometimes a necessary strategy to obtain relief from difficulty. She also, however, emphasised the importance of making a conscious choice to do this, to be mindfully un-mindful in effect. As can be seen, this is a complex area, which was explored further in the trainers' focus group.

7.2.4 Finding a new sense of identity

As participants learned to view themselves and their illness with greater clarity and perspective, over half described experiencing changes in their sense of identity and beliefs about themselves, and in particular how much their illness affected these perceptions. Sometimes these changes partially to pre-dated course attendance, suggesting previous helpful interventions or beliefs. These changes will now be explored.

7.2.4.1 Letting go of old identity and beliefs

Being able to let go of an old sense of self and accept a new reality was explored in most detail in the focus group, where Peter observed:

> *…I think we all have our expectations in life and when something like illness or whatever ever hits you then your life changes, now that doesn't mean to say it's better or worse, all it means it's like you said it's just different isn't it?*

Others in the group agreed, identifying that mindfulness helped them see that *"it's changed it's not gone" (Paula, FG)*, and to recognise they were still of value even if they were no longer able to perform their previous roles. There was some indication in the data of a gendered dimension to this experience. A number of women recognised how much their identity had been linked to what they could do for others. In contrast Clive had been profoundly affected by having to give up work, and recognised how much his identity had been linked to this, but also how readily this identification could then shift to another external label:

> *…so you've stopped being Mr [Job title] and you're beginning to be Mr Arthritis and Angina and that's a bad thing... (Clive1)*

He recognised the key role of mindfulness in changing his identification with any particular aspect of himself, and now described himself just as *"a human being, getting along, doing the best I can"*. Michael also observed no longer feeling his identity was so linked to particular aspects of himself; this reduced the stress which came from struggling to defend them: *"this was a battle for survival, 'cause my identity was consistently at stake" (Michael1)*. These changes were part of participants' broader experience of discovering their beliefs about themselves were not always accurate, which will now be considered.

7.2.4.2 Acknowledging but not identifying with my thoughts and illness

A number of participants noted how mindfulness enabled them to view their negative, self-critical thoughts from a more detached perspective:

> …I was very down on myself, 'I'm useless and stupid and pathetic' and being able to, instead of pushing them away, being able to actually put them in front of me and say 'I know you are there I'm just not going to listen to you'. (Christine, FG)

Drawing on Breathworks' teaching, they came to realise that their thoughts were not necessarily a reflection of who they were, and could therefore be related to differently. This was a powerful change in some instances, creating freedom to acknowledge the thoughts without necessarily believing them, and thus gaining more sense of choice about whether and how to respond to them. In another aspect of 'seeking the pleasant' (7.2.2.1), participants recounted choosing to focus on positive thoughts, and working more kindly with negative ones rather than being drawn into blame and self-criticism:

> …it's the thoughts that it helps to, you know I'm lying there thinking, "no, alright thought go that way", and I get back into concentrating instead of you know getting tense and upset because I can't get shut of these thoughts, I do it in a gentle way. It's, the whole thing is gentle... I'm not bashing myself up with them. (Shirley2)

Having an ability to dialogue with the thoughts from a more objective place had the effect of broadening people's sense of identity as they realised that *"there's a me that isn't all this stuff that's going on in my head" (Helen1)*. For Michael, the ability to look <u>at</u> thoughts rather than <u>from</u> them had brought about a helpful change of perspective on his illness, as he came to understand that:

> … there are stories I tell myself about me, and that these aren't necessarily true, and realising that in fact the personality is not fixed. I've thought of myself in a negative way, as a person with depression, that this was who I was – but actually this isn't me, and I can see that now. (Michael2)

These ideas, which draw on Buddhist teachings about the changing and illusory nature of the self and of all experience, offered some people a valuable new way of relating to difficult thoughts and beliefs. As was explored in 7.2.2.3, experiences no longer had the same sense of permanence and fixedness, and therefore had less impact. People were significantly less identified with the negative thoughts that had been a major contributor to their experience of illness or, in some instances, part of the illness itself.

More broadly, participants observed how mindfulness helped them to see their illness in the context of a wider self, which was often an important change:

> …I think although I've got quite a lot wrong with me, I don't <u>perceive</u> it as being things I've got wrong with me, it's not the focus of my life, they're just the things that bugger you up, it's not the same thing at all. (Barbara1)

Although it was not clear from Barbara's interview whether her perception resulted from practising mindfulness, it captures participants' recognition that although they may be living with significant difficulties, their illness was not who they were but only one small part. Reflecting the idea of the 'bigger container' introduced in 7.2.2.2, they could see that

illness had *"shaped who I am, but so have a lot of other things" (Holly2);* they had not become or no longer felt that they <u>were</u> their illness. Shirley observed how she now talked about "<u>the</u> pain", rather than "<u>my</u> pain", reducing her sense of identification with it.

Whilst participants were not identifying with their illness, they were also not ignoring it. Jeannette reflected on seeing her illness as:

…a part of who you are, but it's not the whole of who you are […] it's an important part, it's kind of like a person that I have to take with me. […] I have to think, sort of like when my son was a small child, whatever I was doing I had to think about what was I going to do with him (laughs) and it's a bit like that. (Jeannette1)

As discussed previously, they acknowledged their difficulty but were not defined or limited by it, seeking to find a balance between *"seeing pain but living life" (Wendy1).*

7.2.5   Summary of theme: Getting a new perspective: a changed relationship to my experience

Participants identified a number of ways that their perspective on their illness had been changed by practising mindfulness, many of which are illustrated in Tania's observations:

It's like really having a balloon really, and you have never really put gas in that balloon to float off, and it gives you the chance to float around and see the nicer things in life, and stop worrying about everything and it's a nice feeling, like floating off, and it's a coping mechanism isn't it, they are giving you the coping mechanism to see things <u>as they are</u>, because you have got to be able to live with what you've got, but accepting and being able to live within it, rather than blocking it all out. (Tania1)

Mindfulness encouraged and enabled participants to *'start where I am'* by developing non-judgemental awareness of their present moment experience. This enabled two apparently contradictory changes to take place: moving closer to and facing their situation; and stepping back from and getting a wider perspective on it. By mindfully moving towards their experience, participants acknowledged and accepted the reality of their illness and the difficulties it created. This was often a significant change from struggling with or denying what was happening, and allowed them to let go of regrets and fears and live with their new reality. Focusing on the present moment also helped avoid unhelpful thinking patterns, particularly catastrophising and rumination, which could add layers of 'secondary suffering' to the illness experience. It also enabled recognition of the transient nature of difficult thoughts, feelings and sensations, which helped reduce their power.

Increased awareness and acceptance was sometimes challenging, but almost always seen as helpful. It needed however to be balanced with stepping back from the difficulties and becoming aware of their wider context. Mindfulness enabled participants to notice the pleasant aspects of experience, and to hold positive and negative elements together within a 'bigger container'. This diminished the prominence of illness in their lives without ignoring its real impact. Mindfulness thus had a key role in developing people's ability to observe their immediate symptoms and their overall condition with more detachment, but *"not in a cutting off way" (Michael1)*. Joanne succinctly explained:

> *… it is a bit like sort of standing apart from yourself, not watching yourself exactly […] it's kind of being apart of yourself at the same time as being there. (Joanne2)*

These perspective changes often impacted on participants' sense of identity. The illness no longer had such a defining role, but could be seen as something people <u>experienced</u> rather than who they were. Negative thoughts could also be viewed in a similar way. Increased awareness and acceptance allowed inaccurate and often unhelpful self-perceptions to be let go of, whilst being able to observe experience with more detachment offered participants a sense of freedom and choice.

Getting a new perspective thus had an important role in enabling participants to feel more positive about themselves and their ability to cope with their illness.   The next theme explores this in more detail.

7.3   Feeling equipped to cope: having more resources, confidence and control

When faced with the navigating a difficult journey, a change in perspective can be very powerful in affecting how it is experienced, making it less overwhelming and unpleasant. One important factor in this is how well resourced to cope with the challenges of the journey a person perceives themselves to be. Changes in self-perception can transform how a situation is viewed, even when the external circumstances remain unchanged. From early in the analysis, a key feature identified in participants' experiences was how they felt better equipped to cope with their challenging situations and do more to help themselves:

> *I couldn't find comfort in anything before, the doctors, the consultants, anything else that I did there was no comfort in it for me, and this has given me everything that I need really to, to comfort me with living with the condition you know, so I think it's just the right thing for me as well. (Tania 2)*

By feeling better resourced, participants were able to deal with the difficulties of *'starting where they were'*. They had tools, ideas, language and support, and therefore felt more confident and in control of their journey. Six aspects of this theme, outlined in Figure 7.4, are now explored.

Figure 7.4 *Feeling equipped to cope: categories and sub-categories*

7.3.1	**Having a range of accessible tools and skills I can use in everyday life**
	7.3.1.1 Having a structure, permission, something to do
7.3.2	**Having new ways to understand and talk about my experience**
7.3.3	**Feeling supported, connected, less isolated**
	7.3.3.1 Finding it difficult: not feeling part of the group
7.3.4	**Gaining confidence and competence in managing my condition**
	7.3.4.1 Seeing it's possible to live well with illness
	7.3.4.2 Discovering, feeling confident mindfulness can help
	7.3.4.3 Feeling competent, able to do something for myself
7.3.5	**Having more control and choice in my life, responding not reacting**
7.3.6	**Knowing and understanding myself better**

7.3.1   Having a range of accessible tools and skills I can use in everyday life

This idea was strongly represented in the data, and the language used by participants reflects Breathworks' description of offering a 'toolbox' of ideas and techniques from which people can select what work best for them. Mindfulness is at the heart of this toolbox, but taught in a variety of ways: as a 'formal' meditation practice and in 'informal', applied forms.   The provision of these tools was clearly of great value in translating mindfulness into skills which could readily be applied to life:

> *…it's literally providing tools, rather than just helping people find out what the problem is, in some situations that's obviously very, an excellent idea for where that person's at, but this is actually giving people some, practical ways of moving themselves on. (Hannah1)*

Many people referred to the value of the tools in general, and also to individual practices and resources which they had found helpful. The ways that people applied these tools to their lives are explored in detail in the next theme; the significant point here is that having access to these resources contributed to people feeling equipped to cope with their condition and their lives as a whole.

Various specific aspects of the tools were identified as important. A number of people appreciated the <u>range</u> of skills and strategies offered. This provided the freedom to select what was appropriate to their needs, rather than either having to take on a fixed 'package' or feel guilty about being selective. It also gave a sense of having resources to meet different needs, either over a period of time or in different situations.   The <u>accessibility</u> of mindfulness tools was also emphasised as particularly valuable, participants noting how they could be taken and used anywhere, whenever a need arose:

> *…the breathing technique,….] like if we're going shopping and we're in the car, the wife will go in a shop or something [unclear], and while I'm in the car, I'm doing it without thinking, you know, if I can't sleep at night, I will do it. If I'm in a bit of pain or discomfort, I do it. (John 1)*

Mindfulness practices were also seen as accessible over time: they could be tried out immediately on learning, but were always available to return to after a break in use.

> *…even when your meditation is like <u>erratic</u>, [….] it's…, it's like as if there's a thread connecting it and you can always go back to it and, settle into it again, you know, it stabilises you I think. (Clive 1)*

A number of people were familiar with some of Breathworks' ideas and practices prior to attending, but highlighted the course's significant role in enabling them to apply this knowledge and skills to their lives more effectively. Sometimes this was because the course acted as a reminder or reinforcement of existing knowledge or, less frequently, enabled them to better understand what they were already doing. Notably in a few instances it enabled people to apply the knowledge or practices to their illness in a way that they had not previously done:

> *JL: [….] were you already involved in the Buddhist meditation before that?*
>
> *Lesley: Yes I was doing it before, but I hadn't sort of connected it to my health condition, they were two completely separate things in, I don't know why I'd never connected them. And it was like a eureka moment, so yes now I realise the importance to my mental health but more to my physical health (FG)*

Despite the emphasis on the 'toolkit' nature of the mindfulness practices and ideas, nearly half the participants mentioned having difficulties with particular tools. These struggles are explored more fully in *7.4a.2.4.*

7.3.1.1   Having a structure, permission, something to do

Quite apart from any specific benefits people gained from the particular mindfulness tools, the value of having a structure to work with was identified as important in a number of ways. Hannah, living with long term depression and pain, explained how the body-scan gave her something positive and helpful to do when she lacked motivation in the mornings. It also gave her information to help her manage the pain more effectively, as is discussed in 7.4b.1. A similar sense of *"having something <u>to</u> do…" (Joanne2)* was identified by Maya and Joanne, who both experienced anxiety and feeling overstimulated and unable to stop; they found the meditations provided a structure which helped to counteract this tendency. Others, in what seems to be a related idea, described how the tools gave them permission to stop, which they might not otherwise have given themselves. The mindfulness practices therefore help create new patterns and structures in people's lives.

7.3.2 Having new ways to understand and talk about my experience

In addition to practical tools, Breathworks teaches a range of mindfulness-based concepts which offer a different way of relating to illness, as has been explored in the previous theme. This section identifies how these concepts and ideas significantly affected some participants' sense of feeling equipped to cope.

Firstly, a number of people reported a powerful experience of learning something that helped them to make sense of what was happening in their lives. This often particularly concerned gaining insights into how they were relating to their condition, and how their existing strategies were adding to their suffering and difficulties. Helen reflected on the value of being introduced to a particular idea of non-mindful responses to suffering:

> *I think there were certain things that the trainers said which really struck me. I remember at one point when they first described the blocking/drowning concept, I think that was a really important hook for me because I could actually see that blocking and drowning was what I'd been doing since the pain had started… (Helen 1)*

This sense of recognition was very important for some people: it helped them understand what had previously felt bewildering and overwhelming.   The concepts also provided a language enabling people to describe their experiences and to communicate them to others; this was particularly apparent in the focus group discussions. This increased some people's sense of control, as is explored further in 7.3.5. In addition, discovering that their experiences reflected familiar patterns reduced the isolation many had felt, as explored further in the next section. The feeling of recognition was part of a strong, more general experience described by many participants, that what they were learning 'made sense' and related to their experience:

> *….it just rang true, it were so-, you know, it rang true. I were just so impressed wi' it because it all seemed to work just right... (Clive 1)*

This gave them confidence that *"this is really important, there has to be a way in here" (Helen1)*, which motivated them to continue to engage with the course and mindfulness practice.

7.3.3 Feeling supported, connected, less isolated

Many people commented on how living with a LTC could be an isolating experience, and how the course reduced this isolation in a number of ways.

> *But when you meet people that say "I'm suffering this kind of pain", oh, and you sit and listen to them talking about their pain and you sit and you think "Oh my God, thank God, it's so nice to..!" it's, it's not that it's nice someone else has got pain but it's nice that somebody else knows and understands what I'm feeling and how I'm feeling, it's so good to know there are other people out there that are feeling the way I'm feeling and, this world, I'm not alone with my pain. (Lydia 1)*

The majority of these experiences relate to being in a supportive group situation, rather than being particular to mindfulness, but there are aspects of this experience which seem to be influenced by the wider Buddhist philosophy on which mindfulness is based.

Being with, and sharing experiences with other people with LTC was a powerful experience for many. This largely related to being with 'fellow travellers' going through their own difficult experiences. For some people it was the first time they had been in a situation where they felt understood or met other people living with similar struggles with illness or pain. A variation of this was described by Wendy, who identified herself as having lived 'successfully' with a number of lifelong and long-term health problems. She reflected on how 'success' could bring isolation from both the disabled and able-bodied worlds, and appreciated being with like-minded people who were taking responsibility for their health in a positive way.

The group experience also provided opportunities to exchange practical information about living with particular conditions, and to simply spend time with other people. Most of the research participants were no longer working as a result of their illness, and many had had to limit their activities in other ways, so the course gave a chance to build relationships, some of which had continued after the course ended. As described in 5.2.1, Breathworks places a strong emphasis on on-going support and creating a sense of community between participants. This helped to reinforce the feeling of support and connection which encouraged and assisted participants in maintaining their practice after the course, as discussed in 7.4a.2.5.

As outlined in 5.2.1, Breathworks' distinctively emphasise kindness and 'kindly awareness' meditation. This practice draws on the Buddhist belief in the interconnectedness of all life and how people's suffering can be reduced by the realisation that, at a deep level, they are not separate or isolated. This meditation was identified by some as particularly valuable:

> *Even when you are feeling isolated, because illness is very isolating, and kindly awareness practice you know helps you to get over that to some extent. Feel that you are connected even if you have had a day where you haven't seen anyone and you have spoken to anyone on the phone and you are feeling lonely and isolated you can do that and have that feeling. (Rosalie 2)*

This experience of greater connection is explored further in 7.5.1.8.

7.3.3.1 Finding it difficult: not feeling part of the group

Breathworks' policy of teaching groups with a wide diversity of conditions also affected participants' experiences of connection and support, in both positive and negative ways. For some people, being with others experiencing greater difficulty than them was *"an eye-opener" (Robert 1)* and prompted a realisation that they were fortunate and managing well by comparison. For a few however, the comparison created or reinforced a sense that they did not have a *"proper illness" (Helen 1)* or were less 'deserving' of being on the course. The two people who expressed this most strongly, Helen and Tania, had both struggled a great deal to come to terms with their conditions, and were therefore perhaps more likely to respond in this way. For both however, this feeling resolved as the course progressed and they moved to a different relationship with their condition.

Similarly, some people who found they had a dissimilar condition to others initially felt not part of the group, or that the course did not apply to them. Others found the diversity difficult, particularly the inclusion of people with both physical and mental health problems. However, again this experience generally gave way to recognition that everyone suffered and struggled in similar ways, and a sense of *"we're all human beings doing the best we can" (Michaela 1),* as was explored in the previous section.

7.3.4 Gaining confidence and competence in managing my condition

The tools, concepts and support identified above equipped participants to manage the challenges of their condition and life of their life more effectively. This resulted in them feeling more confident and capable, as will now be illustrated.

7.3.4.1   Seeing it's possible to live well with illness

A number of participants commented on the inspirational example of many of the Breathworks trainers, who provided a powerful demonstration of using mindfulness as an effective tool in managing their own LTCs. This gave participants a sense of hope that it was possible to live well with their own difficulties.

> *…this lady had had awful health issues too and then she had done the mindfulness and then she decided she was going to be a mindful teacher, but so she'd come through the journey so she could say "well look I've been there this is what, this is what happened to me and you know now this is what I do". (Holly 2)*

The trainers' own struggles also made it more possible for people to receive the sometimes challenging ideas that were presented about how to live differently using mindfulness, particularly in relation to acceptance of their condition.

7.3.4.2   Discovering, feeling confident mindfulness can help

As people started to practise mindfulness, many identified quickly seeing changes in their lives. This created confidence that mindfulness was going to make a difference, either by directly reducing symptoms or through providing more effective strategies for managing them. This in turn gave people motivation to continue practising (see 7.4a.2.2), which then produced further benefits. As a result, participants felt more able to meet the challenges of both their on-going condition and, in some cases, potential future deterioration:

> *I'm just so happy I'm doing it cos I know it's going to help me with whatever next happens er, I've <u>no</u> doubt about that at all it would be very upsetting if I had something like Alzheimer's cos all sorts of connotations there, but it's how to deal with it, how to look after oneself and other people because of it. So it's there for me. (Shirley2)*

Having strategies to prepare for difficult situations was identified as beneficial to many aspects of people's lives, not just those related to illness. For instance, some described using meditation before meeting difficult people, as is discussed in 7.5.1.8. Although this was not explicitly stated, it also seemed that having confidence in the value of mindfulness was likely to increase people's willingness to engage with the challenging process of 'moving towards difficulty' identified in 7.2.1. Knowing that this process offered benefits would increase their ability to <u>continue</u> to engage in this way, which is necessary to negotiating the on-going process of living with a LTC. This is one of the many ways that different aspects of people's experience acted in 'virtuous circles' to reinforce each other, which are discussed in 7.6.

7.3.4.3   Feeling competent, able to do something for myself

A number of people recounted how learning and practising mindfulness had given them greater competence to manage their condition for themselves. They had tools, skills and strategies they could employ when they needed, and which they knew would make a difference.   Some particularly emphasised the importance of having *"something I could do for myself" (Helen1)*, which in some cases was contrasted with their experiences of the health system:

> *…rather than what I had been doing which is going along to people in the NHS and having things done to me, or sometimes going to osteopaths and things like that and having treatments done to me… (Helen 1)*

A few people appreciated finding a 'drug-free' approach to help them manage their condition, partly because they were often already taking a number of medications, and partly because it was seen as:

> *…an enabler […] sometimes I'll put a CD on and think 'Oh I don't want to listen to that today' […] and put another one on, whereas with the pill it's that chemical that you take in your body, you're not quite sure what it's doing... (Nell1)*

People felt less helpless in coping with the challenges they faced in relation to their illness, and more competent in looking after themselves effectively. This then increased their self-esteem and sense of control and autonomy, as will now be explored.

7.3.5 Having more control and choice in my life, responding not reacting

Almost all participants made some reference to feeling more in control of their lives, and sometimes to having re-gained control having previously felt overwhelmed by their illness. Helen noted, *"…it makes me feel more that I'm in charge and not my pain" (Helen2).* In particular, people reported how using mindfulness had helped them to be less reactive, and more able to choose their response. As explored in the previous theme, they recounted taking a step back and noticing what was happening rather than simply being caught up in it. Barbara observed how mindfulness *"gives you the space to intercept things that otherwise you might just act on" (Barbara1).*

From this position of awareness, participants could ask themselves what they wanted and make a more informed, considered decision about their behaviour; to *"… stop running on auto pilot" (Michaela1)*. This pattern of responding not reacting was identified in relation both to external events and internal thoughts and feelings.

In relation to external situations, participants were able to maintain a calmer, more centred place in themselves when dealing with stressful situations or people. As a result they were less likely to react in ways they would regret or which might cause them stress and aggravate their condition. In relation to their internal experience, as discussed in 7.2.3.2, many participants recounted being able to observe negative thoughts and feelings but not being driven by them: *"getting a bit more of a balanced view" (Holly1)*. Helen described how having more space around her experience gave her freedom and *"…some element of choice as to whether I believe the stuff that's going on in my head or not (Helen1)".* This change opened the possibility of deciding how they wanted to act, or what they wanted to pay attention to, including sometimes deliberately shifting their focus onto something more positive, as noted in 7.2.2.1. The ability to avoid triggering their symptoms or unhelpful thinking patterns increased participants' sense of being able to manage their condition and their emotional reactions: *"It's like you are taking control whereas the anxious takes control" (Maya2)*. On a bigger scale, John identified how being able to *"really evaluate what's going on" (John1)* with the complexity of his illnesses helped him to feel radically more in control of his life.

The recognition that they <u>could</u> behave differently was a powerful discovery for some, which gave them a strong sense of choice and control in their lives as a whole, whilst others identified regaining a sense of autonomy they had lost touch with due to illness:

> *…I can change me, I can change my way of being, I can change my ideas, I can change my reactions… (Michaela1)*
>
> *I've come from that dark hell, and it was a dark hell, into where I do have some say over my life. (Shirley1)*

At the same time, participants described becoming clearer about what they could <u>not</u> control, and of letting go of struggling with these things. This is explored further in 7.4b.3, and often related to recognising that whilst their illness may be outside their control, they had some choice about how they responded to it:

> *I think it is the sense of choice, […] rather than feeling I am being battered around, is really important I think (Helen2)*

Participants noted making active choices to look after themselves better in a range of ways explored in 7.4b.2.2. They also identified how mindfulness tools gave them more options with which to manage their condition or situation. Hannah noted that she could now plan how to respond to her pain and depression, rather than being *"just stuck <u>in</u> it" (Hannah1).* In relation to negative thinking patterns, Michaela described having *"…the tools to sort of say 'stop' […] I don't have to go there and I don't need to go there, and also if I want to go there I <u>can</u>" (Michaela1).*

As with many aspects of practising mindfulness, participants noted that these changes were not always easy to make, and required regular practice. Overall, however, they gave participants a greater sense of freedom, of *"deciding where my life goes" (Helen2)*, which was not dependent on their illness or future prognosis.

7.3.6 Knowing and understanding myself better

Participants observed how using mindfulness to observe what was happening in and around them had enabled them to develop a better understanding of themselves:

> *...you know yourself better. I don't say you know yourself completely but you begin to know yourself better and what, what drives you, umm, yeah, … you become wiser (Clive 1)*

This knowledge provided participants with valuable information and insights. Many noted that they had become more aware of their body, and of the physical sensations they experienced such as pain, tension or tiredness. Although this may appear undesirable when not considered in context, the sense of being more *"tuned-in to how I feel" (Holly 2)* enabled people to better understand the triggers for those sensations, and to identify what was most effective in relieving them. A similar pattern was identified regarding thoughts and feelings, whereby people found they had more awareness of their mood or patterns of thinking and what may impact negatively or positively on these. Over time, this awareness gave people a greater understanding of their habits and patterns of behaviour and thinking, and of their own needs and limits. Participants frequently referred to the value of

this greater knowledge and understanding, and how it enhanced their ability to manage their condition, as is explored in depth in 7.4b.1.

7.3.7   Summary of theme: Feeling equipped to cope: having more resources, confidence and control

Mindfulness enabled participants to feel more equipped to cope with their illness in a variety of ways. They had a range of accessible, practical tools, and new ways of understanding and talking about their experience of illness. They felt less isolated, particularly valuing feeling part of and supported by the Breathworks community. Seeing the positive examples of the trainers living well with illness provided inspiration that mindfulness could make a difference. Practising mindfulness also often rapidly brought significant benefits in their own lives. This in turn created the motivation and confidence to continue with the sometimes challenging new ways of relating to their illness, and a sense of competence in managing their condition. Discovering they could change how they responded to their experience increased participants' feelings of control. They felt more able to choose their response, rather than being caught up in a cycle of reaction which often added to their suffering. Mindfulness also gave participants greater understanding of their condition and habits and patterns of behaviour, which contributed to their sense of control and autonomy.

Feeling equipped to cope was key to enabling participants to manage their health and other challenges in life more successfully. Through practising mindfulness, they were also more able to face the reality of their situation, as considered in the previous theme. As a result of these two changes, participants highlighted a range of ways their behaviour had altered, which will now be explored.

7.4   Doing life differently: finding my way with my illness, with mindfulness

The first theme explored the changes people identified in their perspective on their illness, both becoming more aware of and accepting of what they were experiencing, and more able to locate their difficulties within a wider context. The second theme discussed how having new tools, insights and support gave participants a sense of being more able to cope with their condition, and a feeling of greater confidence and control. In this theme, the focus moves to changes in behaviour and thinking that participants identified as a result of these new perspectives and tools. It identifies how by *'starting where I am'*, i.e. accepting and understanding the new country they inhabited, they were able to *'do life differently'* in a number of significant ways.

This theme is divided into two sub-themes: 'Finding my way with mindfulness', and 'Finding my way with my illness'. The first explores how participants described their engagement with mindfulness and meditation practice; the second focuses on their accounts of working differently with their illness or condition. These sub-themes, and the

categories they contain, were particularly developed through analysis of the diary-based second interviews. People's ways of working with mindfulness are considered first, as the complexity and variety of their experiences illuminate subsequent accounts of living differently with their condition.

7.4a Finding my way with mindfulness

In this section, participants' journey with mindfulness is followed, from getting started with the practices, through ongoing engagement, and finally exploring how people 'made it my own' by developing their own ways of working with what they had learned. Discussion of participants' accounts of their patterns and choices of practice is also informed by material drawn from their diaries of mindfulness practice. Figure 7.5 details the categories and sub-categories within this sub-theme.

Figure 7.5 Finding my way with mindfulness: categories and sub-categories

7.4a.1 Getting started 　　　　7.4a.1.1 Attitudes and perceptions help *or hinder* 　　　　7.4a.1.2 Positive course experiences 　　　　*7.4a.1.3 Finding it difficult: challenging course experiences* **7.4a.2 Taking it on, keeping at it, finding ways to maintain practice** 　　　　7.4a.2.1 Making time, making a commitment 　　　　7.4a.2.2 Motivated by seeing a change 　　　　7.4a.2.3 Making mindfulness a way of life, finding it becomes second nature 　　　　*7.4a.2.4 Finding it difficult: struggling to establish and maintain practice* 　　　　7.4a.2.5 Finding strategies to support practice 　　　　7.4a.2.6 Research participation as a support to practice **7.4a.3 Making it my own, developing patterns of practice** 　　　　7.4a.3.1 Patterns: practising regularly or responding to need 　　　　7.4a.3.2 Patterns: balancing formal and informal mindfulness practice 　　　　7.4a.3.3 Patterns: practice changes over time 　　　　7.4a.3.4 Choices: Selecting what works best for me 　　　　7.4a.3.5 Choices: integrating or replacing mindfulness with other tools 　　　　7.4a.3.6 Choices: adapting practices to my own needs

7.4a.1 Getting started

As has already been identified, practising mindfulness presented challenges as well as offering potentially powerful tools for change, and it is likely that the research participants disproportionately contained those who had 'successfully' negotiated these challenges. Consequently, the interviews and focus groups considered not only participants' own experiences, but their observations on other Breathworks participants, to explore the factors that influenced people's ability to 'get started' with mindfulness. From this, two main influences were identified: individuals' own perceptions, expectations and motivations; and specific experiences of the course itself.

7.4a.1.1   Attitudes and perceptions help *or hinder*

Many – though certainly not all – participants had had prior experiences which gave them some familiarity with elements of the Breathworks course. Others had not, but described themselves as generally open minded and willing to learn new things. Some remarked that they knew other people whose attitudes were different, and might struggle more with the course as a result, or simply not attend. Perceptions of mindfulness and its Buddhist roots were considered possible influences. Wendy, a practising Christian, commented that many in her church would not be comfortable with the course, and that she had been *"very careful what I told them" (Wendy 1).* The perception of mindfulness as lacking spontaneity and creating an undesirable distance from emotion and experience was also mentioned by a few people. Conversely, for other people, Breathworks' association with Buddhism and spirituality were seen as positive features which attracted them to attend.

The concept of being 'ready' was highlighted by a number of people, who felt they had benefited more because the course came at 'the right time' for them. However, identifying what contributed to this 'rightness' was more difficult. A variety of factors were suggested, but there was not a consensus around these; this probably reflects the complex and individual nature of people's experience. Some emphasised that they needed to have gone through an unsuccessful struggle to resolve their condition in order to be ready to try the radical alternative of acceptance, while others suggested that the level of desperation could sometimes be an important motivating factor. Reflecting the issues explored in 7.2.1, a willingness to acknowledge and engage with their illness was noted as a necessary part of 'getting started'. This related to a broader attitude of being prepared to take responsibility for their wellbeing, and willing to make changes in life to facilitate this, rather than expecting to be 'fixed'. A few commented that some people were not able to let go of their illness because of the pivotal role it had in their identity and life patterns, and would therefore either not attend the course or be unable to engage with mindfulness and the potential for change it offered.

7.4a.1.2   Positive course experiences

Participants' experiences of the course itself were also seen as affecting people's willingness and ability to benefit from mindfulness. Many factors mentioned were not specific to this course, such as physical environment, skills and qualities of the trainers, composition and dynamics of the group, and course content and resources. The predominant experience of most participants was strongly positive. In particular, the quality of the course content and the abilities and approach of the trainers were frequently mentioned. The course was run in a way that met people's health needs, such as a relatively slow pace and responding flexibly to individuals' particular difficulties. The trainers had an important role in supporting participants' engagement with the sometimes challenging ideas and practices of mindfulness. Not only did they demonstrate the benefits of mindfulness in their own lives, as discussed earlier, but they offered acceptance and kindness which had a powerful effect on many people. Some identified feeling believed and taken seriously for the first time; this was particularly important to Rowena who had had a long struggle to get a diagnosis:

> *When you walk in you have got these strange symptoms and none of the doctors, know what it is, for ten years not a single doctor recognised it and they're just odd and some I didn't even tell the doctors because they are so odd […] and when they said to me 'whatever your symptoms are we believe you', that's the first thing they said to me that was revolutionary, that was the only place I've ever been, […] I don't need to go back and do that again, […] but I will never forget that they said that, ever. Cos nobody else out there believes you. (Rowena 2)*

Kindness was demonstrated by paying attention to participants' individual needs, encouraging them to say what would help them be more comfortable, and finding ways to provide what was needed. For some people who were used to ignoring their symptoms, this modelled a profoundly different way of relating to themselves and their condition, which laid the foundation for a change in their own behaviour.

7.4a.1.3   Finding it difficult: challenging course experiences

A few participants had observed people dropping out of the course, although this was not common. The reasons were generally unclear, however, although sometimes appeared to relate to attitudes and expectations as considered in 7.4a.1.1.

Some recalled negative experiences of aspects of the course. Difficult group dynamics were highlighted by a number of participants or, as noted in 7.3.3.1, an initial feeling of 'not belonging' due to seeing their condition as different, or less serious than others. Trainers' inexperience and handling of particular situations also presented a problem in a few instances.

Some people experienced particular challenges with the meditations, which had a major impact on their engagement with them. Maya, who was suffering from anxiety when she first attended, noted that:

> *… some of it was horrible, 'cause I don't think for me meditation, some of it, just sat doing nothing meditation, was really good for me. […] there was at least one or two weeks when I went to mindfulness and I was screaming inside. (Maya1)*

A few participants recalled particularly difficult experiences in meditation which related to personally traumatic incidents in their lives. One participant found lying down with other people in a group triggered memories of childhood abuse, whilst another experienced a distressing reaction to the kindly awareness practice linked to a complex process of grief that she was going through at the time. A third described initially feeling guilt at not being able to bring kindness to someone who had abused her in the past, and also found that meditation sometimes brought to the surface painful emotions connected with those memories. Notably, all of these people had continued to engage with mindfulness and meditation despite these challenges, although for Maya this had been to only a limited degree.

More frequently, as is explored further in 7.4a.2.4 people found that certain mindfulness practices *"just didn't work for me at all" (Helen1)* or they *"didn't see the point in it" (Holly1)*. This sometimes created a sense of 'doing it wrong' or of 'not getting it', often feeding into an existing self-critical mind-set and creating a sense of failure or frustration.

The trainers' supportive and accepting response to these concerns was important in changing these attitudes, such as Christine's experience of finding the CDs unhelpful:

> *…I came back and said 'I can't listen to them and I've done it wrong again' cos I was still in that 'it must be my fault'. And I was told 'you are just a bit further along that path, what do you do?' and I explained how I dealt with it, 'that's absolutely fine that's what works for you'. And I just felt so accepted, […], the whole group and the trainers were just so accepting of everything. (Christine, FG)*

The links to Buddhism, and by association to religion in general, had a negative impact on some people's experience. Although Breathworks is delivered as a secular course, and for many people this distinction was clear, the use of explicitly Buddhist premises and the Buddhist names of some of the trainers did create unease for some, particularly in the early stages. These experiences were ultimately not an obstacle for these individuals to benefitting from the course, but might have prevented someone else from 'getting started'. This perspective has to be balanced, however, against the significant number of people who found the Buddhist context helpful, and were able to take advantage of this to support their on-going mindfulness practice.

7.4a.2 Taking it on, keeping at it, finding ways to maintain practice

Participants' gave accounts of their efforts to work with and maintain their learning after the course. This section explores how they tried to integrate mindfulness into their lives, the strategies they used to do this, and the difficulties this presented.

7.4a.2.1   Making time, making a commitment

Participants recognised that to obtain benefits from mindfulness, it was important to make a commitment to take on the ideas and practices:

> *…the ladies gave us these [indicating CDs] and they gave us the books, and the charts and everything to go home and practice so now we had to, it was homework now that we had to focus on it now, and help ourselves to try and deal with pain and our mental attitude in every single thing we do. (Lydia 1)*

This sense of making time and effort was frequently emphasised, beginning with doing the course homework and attending the sessions whenever possible, even when this presented a challenge in terms of demands on people's energy and time. Most participants had continued this commitment in various ways which are explored further in 7.4a.3. Many people recognised that engaging with and benefiting from mindfulness was an on-going process with cumulative benefits, and not a 'quick fix'. As Michaela noted, *"I mean I'll be a work in progress for life I'll be you know, we're all works in progress aren't we?" (Michaela1).*

Some participants were aware that mindfulness represented a fundamentally different way of approaching their experience, and *"had to just totally re-educate myself in how to live a different way of life" (Nell 1)*. Others did not identify such a profound shift, or recognised that they were *"not there yet" (Wendy1)*, but still intended to keep working with mindfulness in whatever way they could. Maya, who had had a difficult experience of

the meditations and had not continued any regular 'formal' practice, observed:

M	(laughs) I think maybe the meditation helped!
JL	(laughs) Oh dear!
M	Well no, it, …, it doesn't always mean you do some-, I don't enjoy some exercise but I feel good after it. (Maya1)

Almost all participants expressed willingness to continue with what they had learned, and many described an ongoing process of working with the different ideas and practices which is explored further in 7.4a.3. Two exceptions to this were Susanne and Robert, neither of whom identified specific benefits from mindfulness, and whose experiences are discussed in more detail in 7.5.3.1. As mentioned earlier, Susanne had found it unbearable to move closer to her difficult experience and, as it did not prove possible to arrange an interview, it is uncertain whether she had continued to practise mindfulness in any way. She had however attended the course many years previously, so her willingness to participate in the research suggests she may have maintained some connection for at least a time. Robert identified enjoying the course but not gaining the benefit he had hoped for. This led him not to continue practising. Recognition of positive changes therefore appears to offer important motivation for continued practice, as is now explored.

7.4a.2.2   Motivated by seeing a change

Many people observed significant changes in their experience, some of which were apparent after a relatively short time. These changes offered a powerful motivation and impetus to practice.

> …when you come out of doing it, you feel so much better you think, "actually I want to do this again, want to get into that zone or that place again…" (Tania 1)

Observing other people benefiting during the course similarly acted as an endorsement of mindfulness and inspired participants to continue their practice. This in turn led to further improvements in their own lives, thus creating a 'virtuous circle' of benefit.   Further encouragement came in the form of other people, particularly those close to them, noticing a change in their mood or behaviour. This both confirmed their own experience of change and highlighted how this in turn was benefitting others, as is discussed in 7.5.2. Having been aware that their illness had caused difficulties for those around them, this was a further motivation to continue.

7.4a.2.3   Making mindfulness a way of life, finding it becomes second nature

It was clear that for many participants, mindfulness was integrated into their lives in a fundamental way and was no longer *"sort of a thing out there" (Nadia2)*. They had 'taken it on' and, as described more fully in 7.4b, it had impacted on many aspects of their lives. Mindfulness was seen not just as a meditation practice; in fact for some, as discussed in 7.4a.3.3, regular meditation was no longer part of their experience.   It was rather something that had become, at least to some degree, 'a way of life' or 'second nature'. It was no longer always a conscious decision to practise mindfulness, but an instinctive response to the challenges of their illness and their lives:

> *… I wasn't doing it, I was doing what I'm doing, I wasn't thinking "oh, I'm now, I've done my back in, oh shit, I'm going to now handle, I'm now going to think what would the mindful people do?" I di-, you know, I wasn't doing it like that, I was just doing and <u>being</u> how I'm training myself (Michaela1)*
>
> *…I use the breathing for <u>anything</u> that might cause me any kind of stress. […] driving can be quite stressful so I do it when I'm driving, um actually I don't think it's conscious any more I think it's just, it's automatic. (Christine, FG)*

This is not to say that people maintained a state of mindfulness at all times, or that they did not sometimes consciously apply the tools to particular situations, but does reflect the degree of integration that many participants had achieved. *"I'm just sort of aware of it all the time",* Nell commented. For some, participating in the research revealed to them just how embedded mindfulness had become, as highlighted in 7.4a.2.6.

Whilst most participants were continuing to practise mindfulness, they acknowledged a variety of challenges, which are now explored.

7.4a.2.4   Finding it difficult: struggling to establish and maintain practice

Some of the initial challenges in 'finding a way with mindfulness' related to the struggle to engage with the ideas, particularly the issues around awareness and acceptance discussed in 7.2.1. For others, the practices presented more problems, as was noted in 7.4a.1.3. Gloria, who had not meditated before, initially could not see the value of meditation to her situation, whilst many found particular meditation practices difficult. The kindly awareness meditation prompted most negative reactions: not understanding the reason for it; struggling to bring positive attention to 'difficult people' in their lives; or finding low self-esteem made it challenging to offer kindness to themselves, as discussed in 7.4b.2.4. Others could not engage with the breathing meditation, finding it boring, difficult or occasionally anxiety-provoking. Participants also commented on finding certain mindfulness tools problematic, most notably the 'pacing diaries' which were seen as time-consuming and not of immediately apparent value.

People recounted taking time to 'get their heads round things', but also their willingness to do so and, in many cases, their eventual realisation of the benefits of them, such as Holly's account of completing the pacing diary:

> *Um, I did it, I filled it in. I found… I think I found it a bit frustrating. Um, and I didn't really understand what I was supposed to be doing with it. […] you had to fill in a lot of information. And I suppose if I'm honest I didn't really see how an hour's break would make me feel any better at the time, but now I do. […] I think probably I was a bit anti-pacing. […] …… I just was not very open to the idea. Um, I didn't really see that that could help me feel any better… But anyway I was wrong, so [laughs]… (Holly 1)*

Part of the difficulty for some was that the diary required them to *'start where they were'*, to look more closely at their lives and patterns of behaviour, and how these might be detrimentally affecting their health. This was sometimes challenging, bringing unrealistic levels of activity to light and thus highlighting the need to make changes which had previously been avoided or denied.

Many people described the difficulties of maintaining habits of meditation and mindfulness practice, and how it was easy to get distracted by demands in life, particularly those relating to responsibilities towards other people. For some such as Sara and Nadia who were working full-time, finding time was a challenge, with Sara noting having *"learned to push it in anywhere I can" (Sara1)*.

For some, aspects of their condition(s) also contributed to these difficulties. Pain, fatigue, musculoskeletal and neurological problems all affected engagement with meditation, creating problems with concentration, balance, movement and/or finding a suitable position for meditation. Dyslexia made diary completion challenging. A number of people, particularly those with ME/CFS, identified that their poor memory impacted on their remembering to practice, or on their recall of the details of the meditations. Others explained how their own distraction and emotional distress affected their ability to sit quietly and meditate, as highlighted by Maya in 7.4a.1.3. The question of whether certain types or degrees of illness and distress prevented people practising or benefiting from mindfulness was explored further in the trainers' focus group, and is discussed in 8.4a.

Some people identified practical obstacles they had experienced, or recognised could affect others' ability to access on-going support, or indeed to participate in the course at all. These obstacles were generally not unique to Breathworks. Some were illness related, such as physical difficulties travelling to sessions at some distance, and not always in fully accessible venues. Depression impacted on people's motivation to attend events. Lack of time and money could also form barriers, with a few commenting on how the cost of the course and of follow-up events could be a difficulty for someone on a low income, as those with LTCs are perhaps more likely to be.

A very few people identified having difficult experiences of on-going engagement with the TBC (with whom Breathworks is closely associated, as described in 5.3.1). Gloria described experiencing judgemental attitudes when attending meditation classes, whilst two other participants felt they needed to be a 'nicer person' to engage further with the organisation or Buddhism. For Louise, this related to a perception of herself as 'not the sort of person' who meditates regularly. She recognised this belief created a barrier to practice, and this had changed to some degree by the second interview. Thus, these experiences were complex, reflecting how people's attitudes and beliefs intersect with external experience, in this instance an experience to some degree based in a different culture and worldview.

7.4a.2.5   Finding strategies to support practice

In the light of the challenges to practice, many participants emphasised the need for regular reminders and on-going support. A number of ways of accessing this help were identified. Many valued the support offered by Breathworks in helping them develop and maintain new patterns of life. The course resources, in particular the guided meditation CDs, provided a key means of maintaining meditation practice and reconnecting with the course experience. A few also identified how the voice on the CD provided an important comfort, reducing the isolation of illness explored in 7.3.3:

…when you're at home and you've got no-one to talk to, […] and you feel the need, umm, for a friend, and there's no-one there, I find this does help. (Lydia 1)

Breathworks' events such as drop-in sessions, practice days and the annual 'graduates retreat' were widely appreciated, although timings and other practical considerations sometimes made accessing them difficult. Even for those who did not attend, the regular reminders about events were valued, helping to reconnect them to their experience of the course. Those who did attend found them an important way of gaining support and learning from and sharing experiences with others. A few people had attended the course more than once for similar reasons. Four participants had undertaken training to become trainers with Breathworks, a decision they identified as being at least partly for their own benefit in supporting their mindfulness practice.

Some participants had made a link with Buddhism as a result of the course, and chose to attend meditation events organised by the TBC. Some had found other Buddhist or meditation groups helpful, whilst others identified reading or listening to resources on mindfulness and related subjects as their main support. For those with a pre-existing non-Buddhist faith, mindfulness and meditation were seen as something they could integrate with this, with one participant observing how it had opened up new directions to explore in that tradition.

7.4a.2.6   Research participation as a support to practice

A considerable number of participants identified how taking part in this study had been beneficial to their mindfulness practice. This was not generally articulated as a reason to participate, although Maya's decision was specifically motivated by a desire to re-establish practice:

> …I had panic attacks, […] and I've been free of them for a couple of years and they've come back again in the last six months which is one of the reasons why I decided to take part in the study, because I thought well, then I can use the fact that I see you now and then in three months and see if I can make meself use the CDs that I've got and see if they, assist in the improvement of it … (Maya1)

During the interviews, participants often recalled aspects of mindfulness they had forgotten, encouraging them to review or re-engage with practice. This was evident for Hannah, who commented in a follow-up email:

> …the discussion reminded me about using my "toolbox" and its contents, which has helped me get through a tough weekend, pain and depression. (Hannah1b)

Receiving a copy of her interview transcripts also proved valuable for Tania, prompting her to resume more intensive practice at a time when her health was less good. Others noted that the process of completing the diary prior to the second interview helped them be more mindful during that week. In some instances this was because *"it made me actually do stuff" (Rosalie2),* in others it prompted more awareness of their behaviour and thinking:

> …since doing the mindfulness stuff, particularly this week with your diary, I was ultra-conscious of looking after me. (Michaela2)

A number of focus group participants also emphasised how the discussion had prompted them to reconsider tools they had not been using. Additionally, this group seemed to appreciate the opportunity to share their experiences, and in many cases to find common

ground, there being a high degree of consensus among them. Although none of them had trained together, their common experience and the nature of the discussion seemed to re-create the Breathworks course experience for the participants to some degree. This was reinforced by the focus group taking place at the venue where many had undertaken their training:

> *…thanks for the opportunity to come back to the Buddhist centre and just a little recharge of my batteries for a while now and to share with people, and to refresh some of the things that had kind of fallen off my mental blackboard. (Christine, FG)*

It was clear that a number of participants valued talking with others about their mindfulness experiences, prompting them to consider reconnecting more actively with Breathworks.

A number of people also identified gaining new insights into aspects of their mindfulness practice and the effects it had had on their lives. As described in 7.4a.2.3, mindfulness for many was now 'second nature', and the process of describing their experience illuminated for them how they were using mindfulness and the benefits this had brought.

> *… I didn't realise it now until I'm talking to you now, it does do me some good because it helps me think clearer, and do things that are better for me. (Lydia2)*

Sharing their experience helped some people to realise *"just how far I have come"* *(Shirley1).* For others it made them conscious of the ways in which mindfulness was now integrated into their lives:

> *I have found that I use the informal practice, which I didn't realise actually, but I use it every day so that's what it's highlighted to me. I didn't realise I used it every day, I didn't realise I had taken things from the course and they are a matter of course in my life now… (Tania2)*

This realisation acted as an encouragement to continue practice and in some instances gave insight into action that was needed to reinforce these benefits. Michaela described realising the difference that mindfulness made to dealing with people, and deciding that in future she would aim to meditate *"when I know I'm going to say meet with my mother or go to a meeting that might be particularly difficult" (Michaela2).* Completing the diary also provided some people with new realisations, with two participants noting that they were considering continuing to keep a diary as a result.

7.4a.3 Making it my own, developing patterns of practice

This section sets out the various ways that people identified working with mindfulness and mindfulness meditation. This has two broad aspects: the *patterns* of practice they developed, including frequency and regularity of meditation; and the *choices* they made in relation to the various mindfulness practices. A considerable variation in people's experience in these areas became apparent during the first interviews, and this topic was therefore specifically explored during the second interviews, drawing on the participants' diaries of their practice, and in the focus groups. Data from analysis of the diaries is also included in this section to provide further information and insight into this topic.

7.4a.3.1   Patterns: practising regularly or responding to need

Widely diverging views and experiences were put forward by participants in relation to this topic, particularly regarding their relationship to 'formal mindfulness practice'. This is defined as structured meditation, either guided or self-led, during which other activities are put aside, and contrasts with 'informal mindfulness', which is the integration of mindfulness into daily activities. In practice however, the distinction between the two is not always clear, particularly in relation to techniques such as the three-minute breathing space and breath awareness activities, which introduce very short periods of focused mindfulness into daily life. The patterns below thus consider aspects of both forms of practice, the particular form being clarified where it was possible to do so.

Approximately half the interview participants and a minority of the focus group members considered daily or at least frequent formal meditation practice essential to maintaining the benefits they had gained through mindfulness and supporting their changes in behaviour and thinking:

> *I can only speak from personal experience in that you can get away with day or a couple of days, but then if you don't have that almost that little ritual of sitting down and practising […], for me that personal freedom that comes with it begins to sort of decline, fall away. (Michael2)*

As a result, they had worked with the meditations and other practices on a relatively consistent basis since attending the course, in some instances over a number of years. Even if they did not always manage to achieve it, they aspired to a regular pattern of practice. The nature of this varied considerably from a few who undertook to meditate at least once a day to others who expected to do something formal at some point during every week. Data from the diaries confirmed this pattern, with nine (45%) participants recording formal practice every day (although a number of others had also meditated on most days, as discussed further below).

A contrasting pattern, identified by over half the interview participants and a number of focus group members, was using mindfulness - in particular formal meditations - in response to perceived need. Some also maintained a regular practice, but noted that they might increase their frequency of practice at times of particular stress or difficulty, such as sleep problems or an exacerbation of symptoms. Nadia observed finding this approach "*more meaningful*" in dealing with the challenges of her workplace, enabling her to manage her pain and energy more effectively. She identified that in some cases this could involve a number of short mindfulness meditations in a demanding morning. Her full-time work also meant that she made greater use of informal practice during the week, expecting to do some form of longer meditation at weekends. Others also saw mindfulness practices, particularly breathing exercises, as an important resource to draw on when things were more difficult:

> *I would use it a lot more when I'm more fatigued, a lot more and it helps to cope with the fatigue, cos you know you can't do very much but you become frustrated because you can't do much […] and it's days and days of it. So to use something to find an acceptance of it is really good. (Angela, FG)*

> *…there is a definite trigger there is, it's either a physical feeling of, like I say my heart's racing or I feel I'm going too fast naturally and I need to come down. So it's something within, what I've either got to be doing or how my body is feeling, I just need to do it… (Tania2)*

Most participants describing an 'on demand' pattern did not consider themselves to be regular meditators; notably however, this did not necessarily mean that their practice was infrequent. A number of people recounted taking advantage of opportunities to practice throughout their day, either in response to a need or simply because it had become 'second nature' as identified in 7.4a.2.3. It may be that the use of the word 'regular' during the interview implied a more fixed regime than was intended, leading some to respond to the question somewhat misleadingly. Certainly a significant number of those who did not describe themselves as 'regular' meditators were in fact engaging with meditation or other mindfulness tools on a daily basis. This was evidenced in analysis of interview participants' diaries of mindfulness practice, which showed that 75% (15) had practised formal meditation on five or more days during the week, whilst 85% (17) had practised some form of informal mindfulness on five or more days.   Whilst these figures are likely to be higher than usual due to people's increased awareness from completing the diary, and some social desirability bias, they give some indication of the level to which mindfulness formed part of daily activities.

Some participants recognised that they would benefit more from a regular practice, but had not managed to do this, highlighting the challenges explored in 7.4a.2.4. A few observed that they struggled to maintain practice at times when they were more well, and wanted to do this to prevent problems rather than using mindfulness as a *"fix-it" (Helen2)*. Notably, however, some people did not see regular meditation practice as a key way in which they maintained the changes in their lives. A few noted an active resistance to regular practice, considering this could become an over-rigid discipline which could create a sense of failure if it was not maintained. Peter, a focus group participant explained, *"the whole point is you're supposed to use it when it is needed or when you feel like it".* This perspective contrasts with some of the regular meditators who emphasised:

> *…you have really got to keep doing it day in, day out every day, six days, six out of seven days, forty minutes a day if you are going to reap the benefits (Michael2)*

This provides a clear illustration of the different ways people understood and chose to practise mindfulness.

For some people, a pattern of short episodes of meditation or mindfulness, such as the three minute breathing space, provided equal or greater benefit to longer periods of practice, helping them to pause and shift into a calmer and clearer state of mind. Sometimes this pattern related to pressure of time, but for others it better suited their mental and emotional state. Maya found it difficult to tolerate sitting quietly for an extended time when in a state of acute anxiety, whilst for Rosalie, fitting in a long meditation at such times was seen as *"contributing to your feeling that 'I'm all behind, or I'm not on top of things'" (Rosalie2)*. In these circumstances, a short meditation provided a valuable tool. Helen noted sometimes responding to similar challenges by opting for informal mindfulness practice:

… just bring more mindfulness to how I'm exercising, or during the day trying to stop every now and then and get back to where I feel, or really appreciating different moments…"
(Helen1)

7.4a.3.2   Patterns: balancing formal and informal mindfulness practice

Participants expressed a range of views on the relationship between informal and formal practice, and the relative contribution of the two in maintaining wellbeing. A number noted practising informal mindfulness frequently throughout their day, but recognised the important role of meditation in 'topping-up' that mindfulness, such as Sue's account of coping with anxiety around a cancer diagnosis:

… all those CDs and I chose during the day and I did a short one at night 'cause that helped me towards sleep. So I think that sort of <u>backed</u> it all up and during the day I would still get, and completely out of the blue you know and then I just watched my breathing, labelled it, watched it… (Sue1)

Echoing the divergent perspectives in the previous section, some people described long periods of not doing formal meditation, returning to it at times of *"crisis management" (Holly2),* whilst others emphasised that mindfulness in their daily life could only be maintained through regular meditation practice. Clive reflected that for him the two were inseparable, recounting his experience of a period of stopping meditating:

…the mindfulness completely disappeared and I was a different person for that. Err, yes a completely different person, organisation wise and everything. Yes, it was quite disastrous […] I think I thought I had reached a point where I was okay and I didn't need it. […] I thought this condition this place that I had got myself in was somehow not because I was meditating and being mindful it was because that's who I was, which it is who I was but because I had set up the conditions to put myself there. (Clive2)

In all these instances however, to varying degrees, formal meditation was seen as helping to deepen mindfulness and maintain changes in behaviour, perspective and experience. Gloria, who struggled with significant memory problems, also noted:

..the meditation helps me sleep and it calms me down and makes me able to function I would say. Now the mindfulness just gives me the tools to function, perform, like I say put everything where it belongs and then you can find it… (Gloria2)

Informal mindfulness therefore seemed to provide a strategy for managing life, but was supported by the formal meditation, which provided *"a peaceful place" (Maya2)* where greater calm and relaxation could be achieved. Nadia also observed that meditation *"added value" (Nadia2)* by enabling a wider perspective to be taken, a greater degree of stepping back from experience. These distinctions were noted both by participants who meditated regularly and those who practised on a less frequent or erratic basis.

On a practical level, a few people identified finding the formal meditations easier to remember to do, often forgetting more informal practice. In contrast, others noted that mindfulness in daily life was now their main practice and, as will now be explored, rarely engaged in formal meditation.

7.4a.3.3 Patterns: practice changes over time

Some people had maintained a fairly consistent practice since attending Breathworks, whilst others had changed their patterns considerably. Sometimes this related to choice of meditation practice:

> *…you lose parts of your tool box sometimes and then you find them. Maybe months later and think 'oh I haven't tried that one, I'll try that' (Paula, FG).*

Practices, particularly kindly awareness meditations, which had initially seemed unhelpful or irrelevant, were sometimes later found to be beneficial. Others indicated that further changes of this kind may happen in the future.

The most notable change however, identified by a number of both focus group and interview participants, was a move away from regular formal meditation practice, either for periods of time or as a general trend. This was generally associated with a sense of having integrated the perspectives and insights of mindfulness and therefore not feeling the need to practise the formal meditations as much:

> *…I think in the beginning the formal practice kind of feeds the informal, but over time it becomes more a way of being, so in a way you don't need the formal to feed the informal quite so much because it's there, and the formal practice then becomes, I suppose it's a reinforcement isn't it, and it's a reminder… (Jeannette2)*

Others described initially practising regularly, sometimes for many months or even years, in order to establish a change, but then finding that change sustained itself more readily, only needing less frequent or shorter periods of practice to be maintained.

> *… I felt that I needed quite a lot of time really, because the benefit after, before you see, what it used to be is, you would put the CD on for forty minutes and then you would feel the benefit after […] you would be a completely different person after […] and I liked that person that I was after, it felt better for me, for my condition and for me as a person […] and then I thought "well I don't actually need that length of time", now I can just do this breathing and I get to that person, now I can do the three minutes breathing space I can get to that person. Now I'm more that person in general you see, so there is not this big jump, from where I was to where I want to be, it's evened out. (Tania2)*

Rowena, who had adopted a different practice described in 7.4a.3.5, identified herself as no longer meditating but still practising mindfulness. She considered Breathworks had been pivotal to changing how she managed her condition, stating: *"once you have done mindfulness it doesn't, I don't think it goes away really" (Rowena2)*. Data from the diaries confirmed the importance of informal mindfulness practice in people's lives, with all but one participant (19, 95%) recording some use of it on at least four days of the week, and nine (45%) using it every day. It should be noted however, that 80% (16) interview participants recorded practising formal mindfulness on at least four days of the week. Focus group participants appeared to indicate a greater shift away from formal practice, but as no diary data was collected from this group, it is not possible to explore variations in people's experience in greater depth.

7.4a.3.4   Choices: selecting what works best for me

Just as participants' <u>patterns</u> of mindfulness practice varied, so too did their <u>choice</u> of practices. Notably, almost everyone engaged with only some of what they had learned on the course:

> *I think that's the tool I use the most. It was described to us as a tool box at the time, you know, some things won't suit you, you won't be comfortable with. Some things you will use all the time so I just think of it that way. (Christine, FG)*

This reflects the 'toolbox' approach described in 7.3.1, which encouraged participants to integrate mindfulness into their lives in their own way. Many recalled identifying particular tools they found helpful and others they *"couldn't get on with"* and therefore *"slid off my radar" (Kathy, FG)*, a process which began even during the course. Some differentiated between meditations that felt essential to their wellbeing and those that were *"nice to do at the time, but [..] didn't have a massive impact on my life" (Tania1).* Although these choices often remained in place, a number of people noted returning to other tools at a later stage, as described above.

A wide variety of choices were made by participants. Analysis of diary data suggested the body scan was preferred by most interview participants, although a few practised mindfulness of breathing (3, 15%) or kindly awareness (1, 5%) more frequently. There was particularly notable variation in the use of the meditation CDs. For many, these remained of pivotal importance, some noting that they rarely meditated without them. The CDs were valued for the reminder of the detail of the meditation practices - particularly important for some with memory problems - and the structure and focus they provided:

> *I do bits of it very occasionally on my own but I'm not disciplined enough to. I need… my mind is always, you know, somewhere else so I need that discipline. (Holly1)*

The CDs were also used in other ways, with Lydia describing often benefiting from having them playing in the background:

> *I'm still aware of the voices there like someone in the room with me, whereas I'm still going about my day preparing for my day but a calmer voice in the room with me helping me relax to try and prepare myself for a comfortable day. (Lydia2)*

In contrast, Tania used them less frequently, but identified drawing on their words and tone to help her during stressful periods:

> *I sometimes like talk to myself (laughs) in the meditation way, sort of 'you know, just need to just calm down and need to think about why you're worrying about this that and the other' […]. The things that they say on the CDs, I can do that in my head… (Tania1)*

A few people did not use the CDs at all, or only occasionally, feeling they had sufficiently absorbed the guidance from them to meditate on their own, particularly for shorter periods of practice. Echoing the idea of 'responding to need' identified in 7.4a.3.1, some noted returning to them at times of difficulty.

A number of participants described selecting specific practices in response to particular needs or situations. This ability had often been developed over time as people became more aware of themselves and of the impact of the different meditations. The kindly awareness practice was often used when people noticed *"having a difficult reaction to someone" (Helen1)*, and Rosalie also identified this as most useful in gaining perspective on her situation when she felt anxious. Participants frequently used the body-scan to tune into their physical state and inform decisions about what action needed to be taken. Other, more subtle distinctions were also delineated:

> *Gloria:* So I do the mindfulness of breathing every night, no, body-scan at night and then when I wake up I do the mindfulness of the breathing because that gets me a bit more alert.
>
> *JL:* I was going to say what's the benefit for you of doing that?
>
> *Gloria:* The body-scan it just empties my mind and relaxes me and I go to sleep. Now, I find the breathing one, by the time you've got up it just starts your alertness going. Does build up the energy somehow and gets your alertness going I think. (Gloria2)

Rosalie, who had been working with mindfulness for many years, described similar responses and selecting which meditation to do on this basis. In contrast, Michael questioned whether his current approach of *"choos[ing] the meditations that I feel like doing there and then" (Michael2)* was the most beneficial, considering whether a regular pattern with the different meditations might produce *"yet even greater benefits"*. Balancing 'rules' and flexibility was a recurring theme, which is explored in 7.4a.3.6.

7.4a.3.5 Choices: integrating or replacing mindfulness with other tools

> *…I still use painkillers you know, it's not only just, 'I'm going to do the body-scan' […] Still use a bit of alcohol, still do, you know, distractions, anything else you know massage, bit of acupuncture, I will use anything, […] and this is part of it, it's not the only thing, it's a big part of it… (Kathy, FG)*

As Kathy illustrates, participants found ways to integrate mindfulness with other tools and strategies they were already using to manage their condition. These included: prescription medications; psychological interventions such as CBT, counselling and other illness management courses; and complementary therapies such as reiki and yoga. Some already practised various forms of meditation, including mindfulness. Participants did not see mindfulness as replacing other interventions (although in some cases it had enabled reductions in medications such as painkillers or antidepressants), but as providing additional resources to cope with their situation. Joanne described how she had developed *"a system of breathing which is my own sort of amalgamation of all these things I've learned" (Joanne1)*, whilst Lydia found meditating whilst waiting for her painkillers to take effect a helpful strategy to distract from the pain. Nell observed: *"for me yes, I actually just thought of that, it is part of my medication now." (Nell2)*.

Some participants had explored other ideas and practices related to mindfulness and meditation since the course, and this was evident in some participants' diaries (7, 35%), which recorded use of a variety of other practices. In particular a number of people valued finding shorter guided meditations which they now used as well as or instead of what they

had learned through Breathworks. Others described a process of integrating different aspects of practice:

> *You do everything by the book, you know everything that you have done in your class […] it just becomes a pattern […] But then you start and seem to, in your own mind change them round and take different bits out of this and bits out of that and make something else of it… (Paula, FG)*

Two participants identified finding more physically active practices met their needs better. Maya noted that the *"let's sit here"* meditations did not 'catch her mind' enough to help with her anxiety and distraction, and this had led her to explore other approaches. Rowena had joined a different Buddhist group whose core practice was chanting rather than meditation. Although she had gained considerable benefits from mindfulness meditation, she found chanting suited her active, *"very A-type"* personality:

> *…it's about taking action to, to make things much better, rather than just […] thinking about, meditating about things, actually changing, changing the whole world through Buddhism, actively changing it. My understanding is, anyway. (Rowena1)*

7.4a.3.6　　　Choices: adapting practices to my own needs

Participants described various adaptations they had made to the meditations and other mindfulness practices to suit themselves and their situation. Sometimes these were practical changes, such as targeting the body-scan on a painful part of their body. Others related to changing the language or imagery used; for example Wendy, a Christian, chose to pray for people during the kindly awareness mediation. Another frequently identified adaptation was the use of the body-scan CD to help with sleep:

> *…sometimes I do it, just bit, I just go to bed early and put the CD on, and I start meditation and it just give me the best sleep. And a solid sleep really as well. So although I know they say don't do it to sleep, I sometimes do it to get me off to sleep because I want that, that's what I want, I want to, I want to relax all my body and I want to drift off. (Tania1)*

Like many other participants, Tania's observation in this instance contains a certain amount of guilt. This reflects the fact that the meditations are not taught as aids to sleep or relaxation, the guidance suggesting adopting a posture that encourages alertness. Using the meditation in this way however, or unintentionally falling asleep during meditation, was a frequent occurrence. Echoing many people's comments, Rowena observed, *"I think if you go to sleep that easily your body obviously needs to go to sleep, so I think it's probably beneficial anyway." (Rowena1)*

Underlying these adaptations was a more fundamental issue, articulated clearly by a few people, concerning how decisions regarding mindfulness practice were made. In particular, this related to knowing when to respond to individual needs rather than do what was 'right'. Sometimes, this meant prioritising one 'need' over another:

> *…who's not gonna pick their grandchildren up even if they are aching and tired and sick? I can't not pick my grand-kids up. I'll just do it no matter what the consequences are.. (Clive1)*

In another instance, Helen observed how she would sometimes make a decision <u>not</u> to engage in mindfulness or meditation practice, considering that coming into closer contact with her pain and distress was not helpful at that time. This decision reflects the process of negotiating a balance between moving towards difficulty and stepping back explored in 7.2, and was identified by some as key to 'successfully' practising mindfulness. By bringing flexibility to her practice, Helen was able to work creatively with the tools of mindfulness:

> *…it's kind of trying to kind of walk that balance between pushing away things that you might need to pay attention to, […] but I think perhaps I feel that if I push myself too much to kind of go right up against the pain and have it slammed in my face when it's quite bad, I think that could be a bit too overwhelming for me, and then that could risk tipping me back into depression, though I think probably the greater risk is on the side of totally trying to ignore everything for ages and then having it suddenly overwhelm me, so I think little bits at a time, probably better in terms of protecting me from kind of getting overwhelmed and getting depressed. (Helen1)*

Continuing this theme in her second interview, Helen highlighted the key role of kindness (discussed further in 7.4b.2.5) in navigating this potentially difficult territory:

> *…yeah, it might not be very kind to have to notice the pain too much, but at the same time it's also not very kind for me to be trying to block it out when actually it is there, and not dealing with how I'm feeling, and then end up being overwhelmed after a few days of manic work... (Helen2)*

Similarly, Michael, who had a strong commitment to a regular meditation practice, noted the importance of being responsive and kind to himself, and ensuring his approach to practice took this into account on a difficult day:

> *… it was fairly light following the breath, I wasn't: "you must follow your breath" you know, it was kind of "just keep with it, this is just enough" yes, work with the 'just enough' idea. (Michael2)*

7.4a.4 Summary of sub-theme: Finding my way with mindfulness

Participants identified the strategies and difficulties in establishing and developing mindfulness practice. A complex range of internal and external factors were seen to affect this, including people's health problems. Whilst acknowledging the challenges of changing their behaviour, participants emphasised their commitment to 'taking it on', and for many this had resulted in mindfulness becoming integrated into everyday life. The benefits gained from practising mindfulness provided an important motivation to continue, creating a 'virtuous circle' of positive experience.

Participants had developed a variety of patterns of practice. Some had a strong commitment to regular formal meditation, seeing it as essential to sustaining mindfulness in everyday life. Others maintained a changed perspective without structured mindfulness practice, or used other practices adopted since the course. For many, practice had a responsive element, with greater emphasis on formal and/or more frequent practice at times of difficulty. Choices of meditation or practice varied, some participants having a deep understanding of how different practices met their needs. This had developed over

time as a result of people's greater self-awareness. Mindfulness thus offered both a <u>way</u> for people to increase awareness of their needs, and a <u>means</u> to meet these needs. The role of kindness in guiding participants' choices was emphasised, encouraging them to adapt practices to their own needs, including sometimes mindfully choosing not to be mindful.

Participants therefore developed individual patterns of practice built on an intimate knowledge and understanding of themselves. This understanding was also applied to their management of their health conditions, as will be now explored.

7.4b Finding my way with my illness

As previously reported, participants identified being more non-judgementally aware of their experience, and how mindfulness provided both a means and motivation to develop this awareness. They were therefore more familiar with the territory in which they were travelling, and more accepting of the fact that this was where they now were, at least for the foreseeable future. This section explores how that awareness was translated into working differently with their health conditions. It demonstrates how *'starting where I am'* was not just a change in thinking, but in behaviour. This change was central to addressing the research question, and was one of the major areas of exploration in the second interviews. Participants' research diaries formed a focus for this discussion, providing many specific instances of changes in their lives, as will now be considered. The categories and sub-categories comprising this sub-theme are shown in Figure 7.6.

Figure 7.6 Finding my way with my illness: categories and sub-categories

7.4b.1 Aware of and responding accurately and appropriately to my needs
       7.4b.1.1 Can monitor self, symptoms and respond more quickly, accurately
       7.4b.1.2 Can plan what to do to manage condition, meet needs
       7.4b.1.3 Can make informed choices and decisions about how to live life
       7.4b.1.4   Recognising I can do more, challenging myself, choosing to push my limits
       7.4b.1.5 Stopping sooner, not ignoring my needs, avoiding flare-ups
       7.4b.1.6 Finding it difficult: Becoming aware of not being mindful
 7.4b.2 Becoming kinder to myself
       7.4b.2.1 Not judging myself as much, appreciating myself and what I can do
       7.4b.2.2 Looking after myself better, putting myself first
       7.4b.2.3 Being open with others about my condition and needs
       7.4b.2.4 Finding it difficult: struggling to be kind to myself, put myself first
       7.4b.2.5 Identifying the role of kindness
 7.4b.3 Focusing on process rather than outcomes

7.4b.1 Aware of and responding accurately and appropriately to my needs

Although becoming more familiar with present moment experience could be painful and challenging, participants identified how it offered significant benefits in providing clear information about their state of health and wellbeing. As highlighted in *Getting a new perspective* they could observe the detail of their situation more accurately, and from a less emotionally overwhelming place. This enabled them to respond in a considered and relevant way to their experience rather than simply reacting to it:

> *It's almost as though [I'm] outside of my body, looking in, does that make sense? And seeing the pain, and doing what I can about it… (Shirley1)*

In this way, participants were able to *'start where they were'* on their journey, and take appropriate action in response. This, for some people, was a significant change, as I reflected in the memo in Figure 7.7.

Figure 7.7 Extract from 'Starting where you are' memo

> *What I'm looking at is the idea that actually a lot of people <u>don't</u> start from where they are, they start from where they wish they were, or where they have been in the past, or where they think they ought to be. That can work up to a point, probably quite successfully, but is likely to put significant strain of some kind on your system and life and health.*
>
> *What mindfulness and mindfulness meditation offer is a way to start from where you are. It gives you a range of tools to look at where you are and be able to accept it as the starting point that you're at. This then makes it possible to move from that place towards the destination, which for the time being I'm describing as a satisfactory life. It's not a particularly easy thing to do, because it requires people to look at this place that it would be better not to be in, but what that does is actually give you accurate information to potentially help you navigate out of it.   (1/3/13)*

The connection between acceptance, awareness and appropriate action was frequently identified by participants, and seemed to operate over a number of different 'timescales' in their lives. Although there is some overlap between them, three relatively distinct timescales could be identified: responding immediately to the current situation; planning everyday patterns of activities; and making decisions about 'bigger' life choices. Participants varied in their focus, with some primarily making reference to one timescale and others noting changes in a number of areas. These three timescales will now be explored.

7.4b.1.1   Can monitor self, symptoms and respond more quickly, accurately

This first timescale of awareness and response was mentioned by almost all participants, and referred to the 'in the moment' management of symptoms and experience. People identified being more *"in tune with how I feel" (Holly2)*, and making immediate decisions about how to respond to what they were noticing. This applied both to mental and physical states:

> *I suppose the first bit is, I've become aware of the fact that I'm very ahhg. So the first thing is becoming aware of the fact that you have got a bit wound [up], and when you are a bit wound [up] you breathe shallow. So it's, get myself, […], and so to get a nice deep breath in is, is that you know (Maya2)*
>
> *(quoting from diary) 'Body in pain, unable to clearly state where so engaged in a body-scan to pinpoint the pain and it was like the knee and the hip, needed to rearrange work so as not to place further strain on myself'. (Nadia2)*

These extracts illustrate how mindfulness enabled people to move towards their experience and become more aware of it so they could then take appropriate action. Mindfulness tools also sometimes then provided the best means to address the identified need, such as using breathing techniques to calm stress and anxiety, or some participants' experience of obtaining pain relief from doing the body scan. Mindfulness therefore both provided a way for people to monitor themselves more accurately and then to respond to what they were experiencing:

> *…so it would actually mean if you were in incredible pain or something you would sort of have to stop and think err, "Hang on a minute, what's really going on here?" and then do something about it. (Hannah1)*

Hannah appreciated how, when she was struggling with motivation due to depression, mindfulness tools helped her tune into her physical experience and address her practical needs, which she might otherwise have not attended to. This then reduced her pain levels, which could otherwise add to the depression. Others similarly noticed the value of picking up on unhelpful patterns of thinking or behaviour more quickly, which could prevent mental, emotional and physical symptoms from being triggered or further aggravated. In particular, many people noted how this approach acted as a *"stopping mechanism"* *(Maya2)* to avoid or reduce negative spirals of thinking, as discussed in 7.2.3.2:

> *…you know it's like don't obsess on it, it's about, okay, what is it?, worst case scenario thing comes into it again, and it's like, don't let it go out of proportion… (John1)*

Mindfulness also kept the difficult aspects of participants' experience in proportion, and this clearer perspective then allowed more targeted action to be taken:

> *…at least it sort of focuses you, rather than think[ing], "I'm in pain all over"… (Nadia1)*
>
> *…just to begin to say "well actually no it's here, so what do I need to do?" […] the other day my elbow, it was really sore then realized that I'd been holding a bag that had been over this bit here so I, and I thought "right I've got to change that"… (Nadia2)*

The role of kindness in encouraging people to take helpful action, rather than ignore their needs, was emphasised; this is explored further in 7.4b.2.   Acceptance also had an important role in facilitating this change in behaviour, allowing people to respond more readily to what was <u>actually</u> happening, rather than what they wanted to be happening:

> *…I'm not going to worry that I'm not sleeping and it's now three o'clock, or two o'clock, that means I'll miss an hour from this morning when I was going to read, I'll read now, 'cause there's pain, I can do that now, without feeling that I shouldn't, I should still continue trying to go to sleep… (Louise1)*

Similarly Sue noted how acceptance helped: *"it clears some stuff away and it sort of frees me up" (Sue1)* to take appropriate action such as resting when she felt ill, even though she did not want to. In these instances, *'starting where I am'* enabled people to reduce their struggle and distress with their situation and to take action to self-care effectively.

As identified in 7.4a.2.3, participants emphasised how this level of mindfulness practice was built into their everyday lives, and how they would draw on it repeatedly during their activities. Mostly this was on a spontaneous basis, although Jeannette described planning breaks in her day between activities in order to monitor herself:

> *… it's just, stopping, sitting still, being aware of how I am and how I am might be fine, get on with the next thing, but you know do I need to make a drink?, do I need to go to the loo?, is there something I'm ignoring? just go and do it… (Jeannette2)*

A number of people with co-ordination problems noted finding mindfulness a particularly useful resource when doing physical activity. Others used it to monitor and manage their stress and tension levels in a range of situations, with driving and communication being most frequently highlighted. Some used mindfulness on waking to assess their level of pain or other symptoms; this provided them with information to plan their day's activities. They also often used it to try and ease their symptoms through breathing or relaxation. As discussed in 7.4a.3.1, episodes of intense pain or other distress sometimes provided a trigger for people to practise mindfulness. Another participant recounted determining what to do by monitoring her sense of overload in response to different strategies:

> *…I had tried to talk to myself about it all and I've tried to breathe around it all and tried to do things, but it was just there and I couldn't help that. So I put on the body scan just to just to like I say, more of an intense practice… (Tania2)*

Although the outcome of increased mindfulness was frequently that people took helpful action, a few also highlighted how sometimes their response took the form of ignoring what they became aware of, or deferring responding to it, but from a position of more conscious choice. Helen recognised this in her response to her anxiety and frustration:

> *…I suppose I just become aware and then you have got to decide what you are going to do about it. And quite a lot of the time I will just might push it back again, and then other times I will do something about it, and I don't know what the difference is. (Helen2)*

Others described consciously pushing their limits, as is discussed in 7.4b.1.4. Apart from the direct benefits to symptom management, these informed actions created a valued sense of control, choice and freedom, as was explored in 7.3.5.

7.4b.1.2 Can plan what to do to manage condition, meet needs

The first timescale identified how participants used mindfulness to monitor and respond to their symptoms and situation 'in the moment'. Many also recognised however that where possible, 'prevention was better than cure', and that there were things they could do to manage their condition more effectively. This second timescale therefore related to how people's increased awareness of their experience enabled them to develop appropriate short-term plans and strategies that supported this aim. As identified in 7.3.6, people

were more conscious of their habits and patterns, and how these affected their health. They were more aware of what 'worked for them', and this section explores the ways in which almost two thirds described adjusting their behaviour accordingly.

For a number of people, a key activity on the Breathworks course had been the pacing diary, in which they recorded up to a week of daily activities and the effects that these had on their symptoms. This had often given them significant insights into the management of their condition, and particularly into patterns of behaviour that were aggravating it, often connected to over-activity. People learned to develop a greater understanding of which activities were helpful to them, of their patterns of energy during the day, and for how long and at what pace they could sustain activity without aggravating their condition. They were more aware of the triggers for their symptoms and what steps they could take to avoid them, such as Jeannette's account of coping with episodes of "cog fog" (cognitive fogging) that she sometimes experienced:

> *…I know that it's going to happen to me if I'm overheated, if I don't remember to stay hydrated it's more likely to happen, if I don't take a short break between activities, if I'm frantic it will happen. So I know not to do those things and that makes it less likely to happen but it still might happen, in which case if I just gather myself and breathe I will usually come back to myself. And if I don't then I need to sit down and have a cup of tea, just wait and it will pass and the calmer I am the more quickly it will pass. (Jeannette2)*

Others noted consciously planning their pattern of activity to avoid particularly stressful situations, or to prevent a cycle of over-activity and exhaustion. They were more able to accurately weigh up the costs and benefits of particular activities, and then make a decision about whether to go ahead. A number of people also noted having strategies to prepare for and recover from demanding activities, and using these to plan and manage such situations.   This planning worked in combination with the immediate responsiveness highlighted in the previous section, enabling people to monitor themselves and further adjust their behaviour during the activity:

> *… the whole thing is about awareness, and it's to be really aware of what's going on. If I can see things coming up ahead of me, I am going out the weekend whatever, for two days before I will rest, two days afterwards. And it's about psychologically prepared, physically I will be in the best condition I can be to do it, and yes if we go out and I do get very, very tired, I don't get frustrated with meself for doing that. (John2)*
>
> *I watched my breathing on the day I did the presentation. Cos I know, I watched half the class […] they were all breathing very badly, and for me I know that if I do that then I will suffer with a bad gut […]. And on the PowerPoint […], I had written "slow" as in talk slowly because the faster you talk the less you breathe and I had also written "breathe" and that really helped. So I did use the mindfulness there. And I didn't swallow any air and I was alright afterwards. So that was good. (Holly2)*

It may be this 'real-time' flexibility which Michaela was referring to in her reflection on how mindfulness brought a new dimension to pacing that she had previously lacked:

> *…what I discovered, I knew about pacing from when I first went to the ME clinic so the idea of pacing wasn't new to me when I did the mindfulness course. But you can pace in a non-mindful way, and what the <u>mindfulness</u> course has taught me is to pace much more mindfully and consciously, rather than on auto pilot which I was doing before. (Michaela2)*

As identified previously, acceptance had an important role in the process of change. Some participants were already aware that their behaviour was unhelpful, but their struggle with their condition had prevented them fully adjusting to its impact. A willingness to be kinder to themselves also contributed to positive action; for instance, Wendy reflected on deciding to park nearer her destination, recognising that her mobility was more limited and that her previous strategy of making herself walk further was not helpful.

A greater awareness of their condition also gave some people a greater understanding of the patterns of their illness: *"I know my body now, that the way I experience being tired, or pain, is a certain way" (Louise1).* Helen described recognising when her frequently low mood that *"I kind of accept as normal now"* moved towards depression: *"I see that as a problem and I do something about it" (Helen1),* rather than ignoring this change and risking greater problems later. Tania identified how mindfulness not only helped her to monitor her state, but also provided her with tools to address any worsening of it:

> *…it's something that if I think I'm scared of being ill again and I was getting myself to that point I would do something formal [i.e. meditation practice] because I'm so scared of it happening again, that I would do it formal every day, I would just hammer it because I'm so scared of going down that route that it's like my tool to keep me in check. (Tania2)*

7.4b.1.3   Can make informed choices and decisions about how to live life

The third timescale was a longer term one, where mindfulness enabled people to look clearly at their overall situation and make decisions about 'bigger' life patterns or events. In this instance, the awareness and action was not directly related to particular symptoms and needs in the moment or short term, but to an acknowledgement and acceptance of their condition and the impact it was having on their life:

> *…I would have kept going, I used to force myself sometimes thinking "I know it's going to make me ill if I do the ironing but for god's sake I should be able to do the ironing" and now, haven't ironed anything for about three years. (Rowena2)*

Through this recognition, just over a third of participants noted making decisions to live their life differently in some way that better met their needs, to *'start where they were'* based on the reality of their current situation. (It is worth noting that the focus of discussion, particularly in the second interviews, was on everyday use of mindfulness, which may account for the less frequent mention of these longer-term changes.) Some decisions were relatively small but significant changes in practical arrangements, such as employing a cleaner, preparing less complex meals or investing in more comfortable furniture. Other changes were directly health-related, such as Nell's decision to start using a walking stick, which she recognised was *"about accepting what you've got and using the tools to help yourself" (Nell1).* Occasionally, people had made major changes in their lives:

> *JL: What about the um pacing diary, how did you get on with that?*
>
> *Sara: Well that was horrendous […] there was no pacing in it whatsoever, but that was my life at the time. But I did something about it. Look a year or two years after the course I changed my job. I had the strength to do it because people in my situation, I always tell people, beggars can't be choosers, because I feel like, who wants to hire somebody who is actually registered disabled? So that, that makes it "okay, I'd better keep whatever I have".*
>
> *JL: Right, you don't want to take the risk.*
>
> *Sara: Yes, exactly. But I did it and I got away from it,   (Sara 1)*

Unsurprisingly, many decisions focused on reducing activity and stress, with participants recognising the toll their existing pattern of life was taking on them. In a few cases however, people identified making decisions to maintain or take on certain activities, but with greater awareness, as Jeannette described in relation to continuing to work part-time:

> *I do think that the mindfulness practice helps me to know the difference between pushing the boundaries because that's what I need to do right now and pushing them too far. (Jeannette2)*

This dimension of mindfulness is now explored further.

7.4b.1.4   Recognising I can do more, challenging myself, choosing to push my limits

As noted in 7.2, many participants identified how practising mindfulness had changed their perspective on their illness, thus reducing its impact on their lives: *"giving it its place in life but not making that bigger than it needs to be" (Nell1)*. In addition to this change, some participants observed that having a more accurate awareness of their condition had enabled them to discover that they could helpfully engage in <u>more</u> activity.   This observation was particularly interesting, as it was not one I had anticipated, being counter to the dominant pattern of pulling back from over-activity.

In some instances, people became aware that they were unnecessarily limiting themselves out of fear of worsening their condition or due to a loss of perspective, as Nell explained:

> *…not everything is about the [illness], every ailment or anything I get can't <u>just</u> be about [illness], it's about every day, normal life, isn't it? […] But what you tend to do, you tend to put it all down to your illness and that's what Breathworks kind of taught me as well, you know? […] and you can use it as an excuse as well, because sometimes you actually have to make that effort to, to get up, get dressed and go to your class, because you can say 'Oh, I don't want to go today, 'cause I've got [illness]' and you think 'Oh, come on, that's a real cop-out. Don't make that the excuse, you're just being a lazy sod'. (Nell1)*

This realisation had led Nell to challenge herself on various occasions, and not to withdraw from activities which might be difficult but not harmful. Although not specifically mentioned, this approach also helped maintain connections with other people and the 'outside world', counteracting the potential isolation of long term illness. Others also noted embracing what they <u>could</u> do rather than focusing on their limitations. Helen

identified the importance of language in this context, describing herself 'disabled' rather than 'ill'.

Participants also described sometimes pushing their limits by doing more than was good for them, but with a knowledge and awareness that they were doing this. Rowena described making such a conscious choice:

> *…yesterday I spring cleaned the whole bedroom of my 16 year old son, which is a job and half when you've got a 16 year old, and I knew I was going on too long, but I <u>knew</u> I was going on too long, whereas in the past I wouldn't have even realised I was going on too long. (Rowena1)*

Other participants recognised a similar pattern, which enabled them to engage in activities they wanted to do, but with an awareness of the *"price to pay" (Jeannette2)*, and equipped with strategies to minimise the effects, as described above. On a longer timescale, Wendy reflected how after a long period of anxiety and depression, her improved mental health meant she was now *"overdoing it […] and I'm enjoying life, and I'm able to do it" (Wendy2)*. She recognised that she would have to *"pull back from that someday, but I'm not going to do it yet"*, considering the benefits she was getting from greater engagement with the world, which she saw as part of her recovery, to be worth that 'price'.

It is interesting to note that this application of mindfulness, towards increasing activity, was almost entirely absent from the accounts of participants with ME/CFS, where 'pushing the limits' can often cause significant setbacks. Jeannette recognised this distinction, noting that this strategy, which was potentially helpful in her neurological condition, would not benefit everyone. She also echoed many participants in emphasising the need to retain awareness to stop and pull back from activity, as will now be explored.

7.4b.1.5 Stopping sooner, not ignoring my needs, avoiding flare-ups

Many people identified becoming aware of pushing themselves too hard in ways which were impacting on their illness and wellbeing. This awareness, combined with kindness, played an important role in enabling participants to change their behaviour over all the timescales outlined above. In the short term, this sometimes took the form of stopping their current activity or deciding not to do something they had planned:

> *I can feel myself-, not getting tired now, but I was thinking "ooh I'll go into H (town) this afternoon", and I'm thinking "no, I don't need to, so I'll just have a relaxing afternoon, instead of", and that's learning (Shirley1)*

Participants were more flexible, willing to change their plans in response to their levels of pain or energy. In other instances, they identified approaching an activity with a clear awareness of how it would be carried out:

> *…I actually <u>started</u> on my garden […] and the mindfulness came into that lots and lots. Being aware that I'm supposed to only do twenty minutes, half an hour, and I find that difficult but the mindfulness helped make sure that I was moving on and coming back in for a drink of water, or because I was being mindful of what my body could do. Which is brilliant, it really is … (Shirley2)*

Longer timescales were also affected, such as Rowena's decision to reschedule a training course she was delivering:

> *…I think actually this last few days, yesterday particularly I think it's a sign that I'm doing too much and I have to pull it back a bit now in order to sustain it, so I'm going to talk to my partner about delaying the course by a month. In order to do it well rather than get it done and be ill for month after. (Rowena2)*

This approach also brought about broader behaviour changes, as Kathy, who had attended the course nine years ago, observed: *"it's just I don't rush around doing things like I used to" (Kathy, FG).* In all cases, participants were much more aware of their limits, and prepared to work within them, acknowledging that *"it's tedious at times but it's better for me" (Shirley2).* For many, this was a significant change, but one that had improved their management of their illness, reducing flare-ups or aggravations of their condition. This in turn had sometimes actually increased their capacity and achievements, a benefit explored in 7.5.1.4. It enabled them to be *"living in the moment in the best way you can" (Nadia2);* attending to their needs rather than ignoring or deferring dealing with them and therefore increasing suffering.

7.4b.1.6 Finding it difficult: Becoming aware of not being mindful

Although participants recognised the benefits of a mindful response to their illness, they also acknowledged that it was not always easy to do, and identified a range of challenges. For many it meant an uncomfortable recognition that their existing patterns of behaviour were affecting their health, and a significant change in behaviour. Clive also highlighted discovering how '*starting where I am*' was an ongoing process, with further adjustment needed as his health continued to change:

> *…you see you get used to pacing with your old illnesses and then a new one crops up and you forget about pacing for that, and it's summat you've got to learn if you get a new illness and I think I just hadn't realised that I need to sort my pacing out for this new thing that were going on (Clive1)*

As previously identified, participants emphasised how becoming more mindful of their experience needed to be balanced with what felt helpful and kind at any given moment. People recognised that that they moved in and out of mindfulness, sometimes by choice, sometimes due to the pressures and demands of life, and sometimes because of old habits. Holly reflected on a recent demanding experience where she had reverted to 'blocking' rather than tuning in to herself, identifying that *"the cut off I suppose is […] an old strategy from the past, the mindfulness is a new strategy" (Holly2).* Emphasising the on-going process of engaging with mindfulness, she considered:

> *Maybe I will try that next time and see. […] I think it's a strategy from the past but then I question 'is it actually, is it really the only way you can cope?' Probably not, it's just an old behaviour. […] And it takes time doesn't it to practice a new behaviour? […] there's always things that crop up in life that I think 'can I manage that?', so there is plenty of other opportunities to try it."*

As noted in 7.4a.3.1, participants occasionally observed being less mindful when their health was better and they felt less need to be careful. They also recognised that this

carried risks and were keen to extend their mindfulness into *"how now not to kind of cock it up and make yourself ill again" (Rowena2)*.

Despite these challenges, it appeared that participants became aware more quickly of their lack of mindfulness. Lydia, who had memory problems, noted how difficult she found it to maintain mindfulness practice, but would become aware of the need for it because she found herself *"not coping properly" (Lydia2).* At some level, therefore, she did retain awareness which eventually triggered a return to practising. An increased kindness towards themselves also allowed people to accept this movement in and out of mindfulness with less blame or self-criticism, and to recognise that that awareness was always there to return to. The role of kindness has been referred to frequently throughout this section, and will now be explored in depth.

7.4b.2 Becoming kinder to myself

As described previously, participants were impressed by the kindness of the Breathworks' trainers, and the encouragement to show a similar kindness and understanding towards themselves. This had a powerful effect on many people's thinking and behaviour. Breathworks' strong emphasis on kindness is distinctive within mindfulness training, and this no doubt contributes to the significance placed on it by the research participants. The role of kindness in relation to mindfulness is a complex one, and was highlighted during some of the first interviews as having an important facilitating role. This led to more explicit exploration of this topic in the second interviews and focus groups, the results of which are discussed at the end of this section.

7.4b.2.1   Not judging myself as much, appreciating myself and what I can do

Before attending the course, the experience of illness had negatively affected many people's view of themselves and their bodies. They felt a sense of failure, that they were letting themselves and other people down, and were painfully aware of the things they could no longer do. A number recognised being very self-critical even prior to their illness; their incapacity and struggles had reinforced their judgemental thinking, including in some instances blaming themselves for their situation. These negative thoughts had added significantly to the suffering caused by their illness, creating guilt, anger, anxiety and stress. For some, the changes in these patterns brought about through the course were profound:

> *…I don't feel so much [I'm] putting it on myself now. I think 'well I was bound to be depressed because this happened to me and that happened to me' […] but before it was always pulling myself to bits over it and that's gone a lot since I saw you last as well, I don't have a go at myself all the time. I don't keep putting myself down all the time and I don't persecute myself as much as I used to... (Tania2)*

This significant and progressive shift away from self-critical thinking and a negative self-image was echoed by a number of people. Rosalie noted that having practised mindfulness for many years, *"I actually think I'm worthwhile, you know" (Rosalie1)*. Lydia commented on how she now felt *"normal"* again, and no longer put herself down because of her illnesses, recognising that:

> *…most people [with illness] think they are less of a person than another person and we are not, we are exactly the same, it's just that we can't cope with things like other people can in everyday life. (Lydia2)*

Others noted important, but less dramatic shifts: "I think I am a bit more kind to myself, I've got a way to go yet but I'm not as hard on myself" (Wendy2).

Reflecting the move towards appreciating the positive discussed in 7.2.2.1, participants valued what they <u>were</u> able to do, rather than focusing on what was not possible or comparing themselves unfavourably with others. They felt more comfortable with the person they had become and, to varying degrees, able to let go of the need to be 'doing' and allow themselves to *"just to be" (Hannah1)*. As Paula observed, "*Makes you believe in yourself again doesn't it?"(FG)*. In particular, some realised their value did not depend on their ability to do things for other people, and that their illness presented an opportunity to re-evaluate who they were and their focus in life. As noted in 7.2.4.1, this point was explored most strongly in the focus group and was seen as particularly relevant to women, whose social conditioning encourages these beliefs.

People were more accepting of their limitations and struggles, recognising that their capacity varied from day to day, and that *"what I do today is good enough, it's good enough" (Kathy, FG)*. This also extended to how they viewed their meditation practice:

> *…I still do get distracted but everybody does and I just think well 'you know that's how it is today'. (Rosalie2)*

A number of people particularly identified being more accepting of their body, having previously felt anger and frustration towards it for what it was unable to do, or the pain it was causing. Michaela noted that *"mindfulness has taught me to start remaking friends with my body again"*, having previously *"really, really hated this thing that wouldn't work properly" (Michaela1)*. For her and others, the kindly awareness meditation had an important role in this change, encouraging them to offer kindness towards <u>themselves</u> as well as others.

7.4b.2.2 Looking after myself better, putting myself first

In addition to these changes of attitude, almost all participants identified how mindfulness and kindness combined to affect their behaviour towards themselves. Some of these changes have been described earlier, where participants recounted how *"I remind myself to listen to my body and <u>do</u> for my body" (Lydia2)*, rather than ignoring their needs. A number of people emphasised the role of kindness in encouraging and supporting their self-care, including paying attention to difficult emotions and taking swifter action to relieve physical symptoms.

This attitude also extended to participants paying more attention to their wider comfort and wellbeing. Hannah stressed the importance of *"do[ing] nice things for yourself" (Hannah1)* and recounted buying treats for herself more often, whilst Holly was prompted into buying a new duvet having recognised she was cold at night. Michaela noted how she no was no longer *"neglecting huge bloody great areas of my life: meditation, spiritual stuff" (Michaela1)*. Participants also recounted making time to stop and rest, and being more

focused on their own needs in their choice of activities, recognising, as Clive observed, *"you've got to get you right first" (Clive1).* This meant prioritising activities they found beneficial or enjoyable – including meditation - over those that might meet others' needs, and postponing arrangements and saying 'no' to commitments they would previously have felt obliged to agree to. 'Putting myself first' was identified as a significant behaviour change by a number of people, and one that was not always comfortable for them or those around them, as is discussed in 7.4b.2.4. It was however seen as essential to managing their health better and sustaining the activities that they were engaged with, as Nadia recognised:

> *…I've got to take some control otherwise I'm not going to be fit for doing anything at work, I'm not going to particularly be pleasant to be around, and […] I'll be in a bad place with my depression… (Nadia1)*

Participants frequently identified changing the pace of their activities, slowing down and putting themselves under less pressure to meet self-imposed deadlines and goals. This was seen as an important way of reducing stress levels, which were often a contributory factor in their illness. People's changed attitudes had a key role in allowing them not to push themselves so hard. As noted in the previous section, they were more able to believe their value was not affected by their condition or what they could achieve:

> *You don't have to beat yourself up and fill all your day up and this is what I was doing, thinking I've got to do this today [..] actually it's okay to sit and have a read or just stare into space and it's about calming down, about relaxing and not be so intense about things. And then enjoying what you've got. (Nell2)*

Tania recalled *"allowing [my]self to just be ill" (Tania1)* for the first time when she had to miss a week of the course and was able to accept this without criticising herself. Wendy, who had recently got a dog to support her, recognised this as a major change in how she looked after herself. She also identified how accepting people's offers to walk the dog would be *"about me receiving help more, and that will be good for me" (Wendy1).* This recognition of changes in relationships with others is now explored further.

7.4b.2.3   Being open with others about my condition and needs

Participants recalled Breathworks' encouragement to be open with others about their illness, particularly the emphasis on communicating what they were experiencing and needing. This openness directly related to non-judgemental acceptance of experience, which enabled people's sense of self-worth to be 'unhooked' from their illness, reducing their sense of shame or fear of others' reactions, as discussed above. It was also built on people's greater knowledge, awareness and understanding of their condition and needs. It was therefore not surprising that over a third of participants reported being more willing to tell others about their condition and to ask for and accept help:

> *It was a taboo subject for me. I didn't know how to approach it with anybody and I just felt it didn't fit with me and I felt like if anybody knows me it's not me that, and I didn't understand it so how could they understand it? Now I'm not really bothered I will just tell them now how I've been […] I don't have that uptight feeling with things around it now. (Tania2)*

Participants recounted being more honest about how they were feeling, and about their limitations and needs. They often found others responded positively, being glad to understand and know how to help, and that this led to improvements in relationships.

People also noted being more open about their condition in other ways. Helen described how being more aware of how she felt, and feeling it was acceptable to ask for help, enabled her to decide to see a psychologist. Nell recounted deciding to use her walking stick when with her mother:

> *…I was tripping up all over the place, I thought "What am I doing? This is ridiculous, she has to see I need to use a walking stick." (Nell1)*

This approach clearly brought benefits to the participants, but was also a major shift in their lives towards acknowledging and attending to their needs. It was also not always easy for others to accommodate, particularly when it meant the person was limiting what they could offer. These challenges are now discussed.

7.4b.2.4 Finding it difficult: struggling to be kind to myself, put myself first

As described above, many people had struggled to feel positive about themselves as a result of their illness and resulting low self-esteem. A few, however, encountered particular difficulties in trying to be kinder to themselves or give their own needs a greater priority. In some instances this related to religious beliefs, such as Gloria's comment that *"as a Catholic you put yourself last, you put everybody else before you" (Gloria1)*. This sentiment was echoed by Leah from her Jewish background. Louise recalled messages from her Christian school hymns which suggested that *"anything less than crucifixion, any less than that isn't really the worst it could be" (Louise2),* which made it difficult to validate her own suffering and offer kindness to herself.

Others related their struggle to difficult early experiences. One participant with a history of abuse found giving kindness to herself particularly challenging, which was reflected in finding the first stage of the kindly awareness practice very difficult, an experience shared by others for a variety of reasons. Wendy recognised that her family's behaviour had encouraged her to ignore her condition and contributed significantly to her not being able to recognise her own needs:

> *I was brought up to believe there was not a lot wrong with me, and if I was in pain, it was my fault, that would be the message that they gave out. (Wendy1)*

Participants also noted how their changes in behaviour had an impact on those around them which was not always welcomed or supported:

> *…it's been hard for my family as well because everybody always expects me to, I've always offered to do it, "Leah'll do it" and Leah's done it, and now I'm having to say "No" and I find that hard, and they don't like it either you know… (Leah1)*

Nadia identified particular risks of 'putting herself first' in the workplace, noting that some colleagues did not like her clear boundaries, and that telling her manager about her struggles and needs had been:

> *…a leap of faith […] I didn't know whether she would be, "oh, you know, I understand", or, "well, you know, tough, get on with it, this is what it's like", because you just don't know with what's happening in this day and age, with work. (Nadia1)*

These participants recognised that their beliefs and experiences had profoundly shaped their behaviour, but were willing to try and change their perspective, knowing that this would be an on-going process. The development of kindness and mindfulness seemed to have a pivotal role in this change, and this last section explores the ways that participants understood the relationship between these qualities.

7.4b.2.5   Identifying the role of kindness

As has been explored, many participants referred to profound changes in thinking and behaviour, and of the importance of kindness within this process. Exploring exactly how people considered kindness to have enabled these changes, and how it supported or related to mindfulness within this process, was more complex however. Only six people, five of them very regular meditators, discussed these potential mechanisms in any detail, so this section is based on the reflections of those participants.

As described above, the explicit focus on kindness was seen to counteract the self-critical voices, which many identified as being associated with their illness or personality, which had made it difficult for them to 'give themselves a break' and focus on their own needs:

> *…when you have illness and pain, kindness doesn't strike you as an obvious thing to be… (Clive2).*

The explicit introduction of kindness towards self therefore gave people a new direction in which to focus their activity. Clive considered:

> *…I can't see my practice working without. It's in the peace and kindness that's generated. And I mean how would you hold onto it? […] I think without, without the feelings that go with it, it would be just a system and there is nothing to keep you on track really. (Clive2)*

The encouragement towards kindness to oneself therefore guided people towards making more positive and helpful choices. Holly emphasised that she did not think she would have changed her behaviour without this focus, which had helped her to realise *"that what I was doing was not very kind, and that there was another way to be" (Holly2)*.

Helen considered kindness to be an essential part of mindfulness. She differentiated mindfulness from awareness, suggesting that *"if there is no kindness in mindfulness then it's just awareness" (Helen2)*. Mindfulness for her had an intrinsic quality of connection to both self and others, which meant that *"kindness will come up in there at some point".* Awareness, by contrast, did not have this quality of connection, although it may be a first step towards it. A similar point was made by Michael, who defined mindfulness as:

> *…so it's a warmth, it's not just about "Oh, I am breathing", there's actually a positive quality imbued within it, and so that brings its own underlying sense of comfort as well as confidence, and that's an essential underpinning for mental good-health. (Michael1)*

He went on to explain that it was this positive quality of kindness that led to a seeking for the pleasant, *"softer"* aspects of experience, rather than just being aware of the unpleasant aspects. This view was echoed by Rosalie, who noted that the kindly awareness practice in particular *"makes you look for something pleasant as well as something, you know all your awful feelings" (Rosalie2)*. Michael reflected that his prior experiences of meditation, which had focused on awareness, had often been quite negative because *"the world was too much with me. It was too close on me, it was too much in my face" (Michael1)*. In contrast, mindfulness had provided *"a little bit of distance"* from the painful experiences of depression and anxiety that he frequently struggled with. He considered that a *"cold and dry and neutral"* understanding of mindfulness was off-putting and unhelpful. This seems to echo Helen's recognition of the need to work in a kindly way to avoid a harmful level of contact with difficulty:

> *…then it's just like smashing your face into it, and it's too, that's overwhelming. So, but that wouldn't be mindfulness then, that would be drowning. (Helen2)*

The focus on the kindly aspect of mindfulness thus seemed to provide both a <u>direction</u> for behaviour change, and a different <u>perspective</u> on experience, which may be lacking with simple awareness. Michaela reflected on her knowledge of other mindfulness courses which she considered *"lack[ed] the huge element in that"*, stressing that the kindness:

> *…teaches you to come out of your head, otherwise a lot of mindfulness stuff can be in the head. And it teaches you to come back to what really matters, which is […] what is in your heart and what it is all about. (Michaela2)*

This emphasis on the heart reflects Helen's comments above about the importance of kindness and connectedness within mindfulness. It seemed therefore that for some people, kindness was fundamental to the change process. This may be particular true for the many people who carry strong self-critical beliefs, counteracting the negative messages that would otherwise be motivating their behaviour and thus preventing effective self-care. It may be that for others who are not driven so strongly by such beliefs, simple awareness would be enough to bring about change: they would notice an unhelpful thought or behaviour and naturally correct it. As Clive commented, *"I think kindness is a natural instinct, daily life can knock it out of you" (Clive2)*. It seems likely that 'daily life' with a LTC in an achievement-focused society often leads to kindness being significantly 'knocked out' of people, partly as a result of individual experience and partly because of wider social and cultural messages. In this context perhaps, the active inclusion of a message of kindness within mindfulness is necessary to make it an effective approach.

7.4b.3 Focusing on process rather than outcomes

Although this category is much smaller than the previous two, it identifies an important change in some people's experience and actions resulting from practising mindfulness. Participants described making a clearer distinction between what they were able to control in their lives and what was outside their control. As a consequence of this, they focused their energy and attention on what they <u>could</u> do, and let go of struggling with what they could not. This forms another dimension of *'starting where I am'* as, through mindfulness,

people had a more accurate perception of which elements of their situation were amenable to change, and which had to be accepted and accommodated. In a refinement to this distinction, a number of people identified that what they were able to control in an activity was the process rather than its outcome. This distinction, and its impact, will now be considered.

John described recognising that many aspects of his health were outside his control, but that he had some power over his attitude to it, and the actions he took in response to it:

> *If you're going to go on like a journey, […] you either enjoy the journey, or you're going to fight it the whole way. And the end result is, you've got to go on that journey. So, you know, from there it's like, make the best of it, you know, accept what's going on. You can't change it, there's nothing I can do about that, but what I can do is to make it as smooth a road as possible. (John1)*

He was aware he could not control the outcome of the journey but he could make the journey *"as easy as possible"* by accepting what was happening and *"just do[ing] it"*. Michaela similarly recognised that in any situation, *"you can only do your bit, you can only do your best and you do your best and then you get on with it" (Michaela1).* She identified that this was a significant shift from trying to control everything, including her illness: "*I'm attaching less and less importance to the outcome of things" (Michaela1).* Michael noted the paradox of feeling more in control by recognising *"that you don't quite control anything and [...] it's OK to let go" (Michael1)*. He and others highlighted the liberating nature of this change of approach.

Participants therefore emphasised how they could gain some control of their experience through the choices they made and how they responded to what was happening. As noted in 7.3.5, mindfulness had enabled them to develop this ability to choose rather than simply react. Clive, in considering how he used mindfulness when doing the ironing, identified that he focused:

> *…not so much getting the ironing right but yes, doing it right, […] it doesn't really matter if you don't get it right but it's the implication of wanting to do it right I suppose, yes and you just don't get hung up on it. (Clive2)*

There is a clear differentiation between focusing on process: *"doing it right"*, rather than outcome: *"getting it right",* which Clive found very calming. In the context of health, Nadia reflected a similar distinction in focusing on undertaking healthy behaviour such as eating well, rather than on a goal of weight loss. She emphasised the satisfaction which came from being engaged in a good process, which she could control, and letting go of struggling to obtain a good outcome, which she could not. Interestingly, she and two other participants with strong connections to Christianity, used the example of the 'Serenity Prayer', which I had also reflected on in memos, to illustrate this point:

> *God grant me the serenity to accept the things I cannot change;*
>
> *courage to change the things I can;*
>
> *and wisdom to know the difference. (Reinhold Niebuhr)*

It seemed that mindfulness helped provide the "wisdom to know the difference", enabling people to let go of struggling for perfect outcomes, and instead *"doing the things that I can do" (Jeannette2)*. Although only mentioned directly by about a third of participants, this change of emphasis seems to underlie many of the changes in perspective and behaviour previously discussed, and is therefore an important aspect of this theme of 'doing life differently'. Paradoxically, letting go of particular outcomes may well have enabled people not only to feel more in control of their lives, but also to recognise a wider range of changes in their experience, which are the focus of the final theme.

7.4b.4 Summary of sub-theme: Finding my way with my illness

Participants identified many changes in their everyday behaviour as a result of practising mindfulness. They were able to be non-judgementally aware of their condition and how it was affecting their lives, and had tools to monitor and support themselves. Greater awareness and acceptance enabled people to respond more accurately and appropriately to their needs, to *'start where they were'* rather than where they wished to be. Participants identified making changes on three 'timescales': responding to their immediate experience and symptoms in the moment; making plans to manage their condition on a day to day level; and, in some cases, making significant changes to their way of life. They learned to stop sooner rather than ignore their limits, but also to not limit themselves unnecessarily. They also recognised making mindful choices to exceed their limits and 'pay the price' on occasions. This complex balance of awareness helped reduce exacerbations of their condition, whilst ensuring they lived as fully as possible.

A kinder attitude towards themselves was emphasised by participants as key to these behaviour changes. They learned to be less self-critical, and to appreciate what they could achieve. Although 'putting themselves first' was sometimes a significant challenge, they paid more attention to their own wellbeing and care. As part of this, they were more able and willing to communicate their needs to others. This was facilitated by increased awareness of what those needs were, and by their self-acceptance, which reduced fear of others' judgements. Kindness therefore had a key role in moving people towards positive, self-caring action, and its relationship to and role within mindfulness was explored.

Participants identified differentiating more clearly between what they were able to control and what they needed to let go of in their lives. In particular, an emphasis on process, of 'doing it right', rather than achieving a specific outcome, i.e. 'getting it right', was highlighted. This change of focus related to participants' ability to accept what they could not change i.e. the fact of their condition, and channel their energy and attention into what they could control i.e. their response to and management of that condition. Letting go of particular illness-related outcomes may also have enabled people to fully appreciate the benefits gained from mindfulness, as will now be explored.

7.5   Seeing a change

The first three themes have identified how participants viewed their experience differently and lived differently as a result of practising mindfulness. Clearly these are ways in which they saw a change. This theme focuses on identifying further differences that participants had seen in their lives and their condition, and the effects of these differences on those around them. Patterns and degrees of change are also considered. The overwhelming majority of experiences were positive, but negative or neutral experiences are also identified. Figure 7.8 provides an overview of the categories and sub-categories in this theme.

Figure 7.8 Seeing a change: categories and sub-categories

7.5.1   Identifying benefits for self
7.5.1.1   Seeing symptoms improve or stabilise
7.5.1.2   Coping better with difficult situations, including symptoms
7.5.1.3   Avoiding illness-related problems
7.5.1.4   Able to do more, managing energy better, having something to offer
7.5.1.5   Calmer, less driven, more relaxed
7.5.1.6   Clarity and focus
7.5.1.7   Positivity, optimism, confidence, rediscovering myself
7.5.1.8   Improved relationships, more connection with life and others
7.5.1.9   Better quality and balance of life, changed priorities
7.5.1.10 No negative outcomes
7.5.2   Identifying benefits for others
7.5.2.1   Less worried about me, understand and know how to help
7.5.2.2   Improved relationships: I'm easier to be with, have more to offer
7.5.2.3   Developed or improved their own mindfulness practice
7.5.3   Degrees and patterns of change
7.5.3.1   Degrees of change: it changed my life, it made no difference
7.5.3.2   Patterns of change: immediate benefit, cumulative effect

7.5.1   Identifying benefits for self

A great variety of benefits were identified by participants, covering all aspects of their experience.   This is unsurprising given that although Breathworks focuses on managing illness, the approach it takes potentially changes fundamental patterns of thinking and behaviour. In addition, people came to the course with a variety of needs and found different aspects of the course helpful.   The benefits they gained therefore varied, reflecting their particular needs and the practices they adopted in response.

It is important to note that whilst most participants could see how they had gained from practising mindfulness, this was balanced against the losses and difficulties illness had brought. A number commented that whatever the benefits, they did not welcome having a LTC and would still rather not have to live with it: *"if I could wave a wand or take a pill and not have it then I would do that" (Jeannette 2)*. Having reached a point of acceptance

that this was not possible however, mindfulness enabled them to appreciate the gifts the unwelcome journey had brought, as will now be explored.

7.5.1.1 Seeing symptoms improve or stabilise

Although mindfulness is not promoted as a way of treating or curing health problems, a number of participants found that some symptoms, particularly those created or exacerbated by stress and 'secondary suffering', were relieved by their practice. The most frequently observed changes were in pain, anxiety and sleep, with depression and energy levels also being mentioned by a number of people. Changes in pain were generally temporary, often an immediate benefit of a period of meditation and probably connected to an improved level of relaxation. Sometimes, however, they were very marked and provided a valuable respite:

> *So if I get to the point where I feel that things are getting to me, specially like […] you were having a bad day and the pain is not very nice to you and I do a body-scan, then I know it's going to be alright afterwards. (Paula, FG)*

For a very few participants, changes in pain were significant enough to lead to a reduction in their use of medication. Most experiences were less pronounced, and some noted that the complexity of their experience made it difficult to know if the pain was reduced, or whether the change was in their perception of it. Hannah's account of working with pain and depression using meditation illustrates this point:

> *Hannah: …just for the few minutes that I'm doing it, it relieves the pain and if you can actually relieve it then it also eases it. Just gives the mind a rest from the thinking.*
> *JL: I suppose it's giving your body a rest as well if the pain actually eases*
> *Hannah: Yes. Whether it really does I don't know but it doesn't really matter cos it feels as if it does.*
> *JL: Yes so in your experience it actually feels like the pain level goes down at those points as well?*
> *Hannah: Yes, yes well it means I stop […] thinking about it. For a few minutes or even a few seconds.*
> *JL: Yes okay and will the pain levels stay less after you've done the?*
> *Hannah: Slightly for a while but it may sort of point me in another direction to er, yes.*
> *(Hannah2)*

Other participants echoed this experience of change predominantly being in the ability to cope with their symptoms rather than in symptoms themselves, as is explored further in the next section. This diversity, from definite pain relief to a change solely or primarily in coping, was notable, and did not obviously relate to any characteristics of the participants or their conditions.

Changes in anxiety levels were frequently identified, often reflecting people's sense of feeling more 'equipped to cope' described in 7.3. For some, prolonged and high levels of anxiety were a primary symptom rather than the result of other illnesses, and in these instances changes were also seen:

> *So there's eight of us have all inherited that almost global anxiety and now I think about it, [...] and when we get onto it, it's the area where I've had <u>terrific</u> relief from it. (Barbara1)*

Rosalie, who experienced panic attacks, noted that these had reduced over time, but that she also now had better strategies to use when they occurred, recognising that *"you need to slow your breathing right down" (Rosalie1).* The effect of learning better breathing techniques was identified by a number of people as key to improving their management of stress, which in turn reduced the occurrence or intensity of some symptoms:

> *… there's problems with the colon, pancreas, um and potentially small intestine and so I've got really low energy, I just don't process food properly. Um… and breathing correctly really can help it. So if I'm stressed and I don't breathe properly then I'll get gut problems again. (Holly1)*

For a number of people living with ME/CFS, the link between stress and their illness was clearly identified, and they noticed changes in a number of symptoms, including IBS, sleep and energy, as a result of practising mindfulness. Improvements in sleep were in fact one of the most frequently identified changes, with many people noting a significant difference, sometimes very quickly after starting the course. For example, Gloria, who had suffered from serious sleep and other problems since a traumatic bereavement, noticed improvements within weeks, and continued to use the meditations to help her sleep.

Changes in energy levels were observed by a number of participants. Isobel described having more energy as a result of not fighting her experience and being able to *"work with it rather than against it" (Isobel, FG).* Others experienced the meditations and breathing as directly giving them more energy, with Shirley in particular describing sometimes dramatic changes in her level of energy as a result of meditating and resting for a few hours. This contrasted with her previous experience of just going to bed, which had been much less effective. Tania also identified that she experienced quicker recovery, and now felt she had a *"tiny bit of reserve"* rather than feeling *"drained to nothing" (Tania1).* How much of this change was due to the individual meditations and how much to an overall change in lifestyle is not possible to say, but clearly the process of working with mindfulness had made a significant difference.

For a number of people, depression was a significant part of their illness experience. For some this was a chronic problem they had lived with for years; for others it was more recent and situational, relating to living with chronic pain or other symptoms. In both instances, participants identified varying degrees of change. Michael, who had had long term depression and anxiety, identified *"a remarkable effect" (Michael 1)*, noting that since starting mindfulness practice he had not had had the longest period without more severe depression in his adult life. Clive and his wife Sally (who was present for part of the first interview) commented on the change they had seen:

> *Sally: …basically what it's done, it's stopped the depression, that's how I see it.*
>
> *Clive: Yeah I think it has.*
>
> *Sally: It has, it has, it's a mi-, it's a terrible, thing when you're not well all the time, <u>constantly</u> not well it's difficult to live with I think for anybody. And I think-, when I say it saved your life I think it's just saved your <u>sanity</u>, let's say, which is a big thing. (Clive1)*

Helen, who had been living with chronic pain and subsequent suicidal depression, identified a similarly profound level of change, observing that practising mindfulness had made a substantial difference to her ability to live with her situation.   Others noted less dramatic changes, but described feeling able to manage their depression differently and having more resources with which to respond to it, as considered previously.

Changes in various other symptoms were observed. Two noted a reduction in their blood pressure, and one person attributed a rapid recovery from surgery to the calming effects of meditation. A few people with neurological disorders also noted that their ability to relax and *"breathe into the discomfort" (Nell 1)* helped reduce their symptoms:

> *It physically calms me tremor and, and my, my, my leg tremor and when my ankle starts going up and down, and I get rigid, and because I'm breathing […]I'm just breathing into my arm and my leg, or the rigidity, or the shake or the tremor, calms me down. (Nell1)*

As with the experiences of pain, the improvement was short-lived but helped Nell to manage the discomfort, particularly at night, in a very different way. In contrast, Michaela, whose ME had created an overstimulation in her nervous system, observed that her facial twitches and ticks were *"calmed down",* and were no longer triggered by activities such as going to the hairdresser; this suggested a longer-term change in her body's functioning.

Although changes in symptoms, whether permanent or temporary, were not part of everyone's experience, most had seen significant changes in their ways of responding and coping with their condition, as will now be explored.

7.5.1.2 Coping better with difficult situations, including symptoms

As previously explored, participants' sense of being able to relate to and cope differently with their illness was often significantly altered. Non-judgemental awareness had helped reduce the struggle and distress associated with their condition or symptoms, whilst the meditations and other techniques provided new ways to cope with them:

> *So when I've got pain, which I have, you see I didn't think to mention that it's funny, that's how I'm training myself to be so unreactive I didn't even think to mention it, without your question. (Michaela2)*
>
> *…listening to the CDs also helps me when I get anxiety attacks like on the bus when I travel […] I learnt to breathe, whereas before I would panic and I look for a way of just get, just thinking about getting out of people's way and the more I tend to panic the more I tend to how can I explain it? […] I can't talk I lose speech and then I just start crying […]. But the CDs have taught me to breathe, stop, think breathe, stop and breathe so I don't get myself all emotional. (Lydia2)*

Clive recalled a recent occasion when he had started vomiting blood, and *"just tekkin' it in me stride. […] well you know, it will get sorted out or it won't" (Clive 1)*, whilst Des explained that meditation and breathing had helped him to *"understand a bit more about my feelings, and where I thought I was going, and they've given me strength to look at that place, or try and look at that place" (Des1).* For Jeannette, living with a progressive neurological condition, mindfulness offered:

…a way to live with the uncertainty and the unpredictability of the illness… to find a kind of equilibrium you know, sort of the idea of equanimity… (Jeannette1)

Many people identified how mindfulness extended into how they coped with a wide range of challenging situations in their lives. Sometimes these were health-related challenges, such as John describing patiently but determinedly spending five hours telephoning a succession of health professionals to obtain new equipment:

…using mindfulness and breathing in between phone calls, I were using it you know to gather me thoughts, you know to just calm meself down, calm meself down for the next conversation. And by using that approach you know think about what's going on instead of just going on like a bull in a china shop, I often use it to you know to withdraw from it a little bit, to reflect, then to move on say okay what have we done here, where are we up to? What is the next stage? […] just to go where I needed to be. (John2)

On other occasions, mindfulness provided tools to help manage a range of everyday situations from coping with fear of the dentist or flying, managing the stress of driving or giving a presentation, to helping an alpaca give birth (!). Nadia, one of the few participants still working full time, described using mindfulness to manage pressured situations:

… people do give me lots of um… you know, they ask me if I'll do this, or do that, and it's not the fact that I don't want to do that, it's that sometimes it feels like there's <u>so</u> much, and it can begin to weight you down. So it's about being able to again use that technique of when you feel everybody's crowding in, or there's a lot of expectation, again I can just get into my breathing or get into just doing a quick body-scan and thinking, "right, where am I feeling the discomfort?" and then <u>stopping</u> and saying… you know, taking control of that situation and just saying, "right, just hang on a minute, let's just do it one at a time". (Nadia1)

Many people identified feeling less stressed in life, and more balanced and grounded as a result of their mindfulness and meditation practice. This not only helped them cope with their symptoms but also, linking back to the previous section, had reduced the occurrence of some of them:

… it just has a life of its own angina so you just, you know, I stay chilled and take me time doing things, that seems to keep it in control, but I have a spray if it's <u>really</u> bothering me… (Clive1)

This illustrates the complex, mutually reinforcing relationship between stress and illness, and how practising mindfulness helped to reverse this and create a positive cycle of benefit.

7.5.1.3   Avoiding illness-related problems

Some participants identified how their increased awareness of their body and its responses enabled them to reduce certain problems created by their illness. This was particularly true of those with neurological conditions, where co-ordination and balance were an issue. Jeannette noted that mindfulness had reduced breakages of china, and also helped her to fall less. Both she and Nell mentioned not cutting or burning themselves as frequently, whilst Shirley emphasised how being in the present moment avoided accidents:

> *… it's the mindfulness thinking, it's thinking about what you are actually doing instead of thinking of something else or the next job it's very difficult sometimes to bring your mind down to <u>exactly</u> what you are doing, and it does go astray and that's when the mindfulness does come in <u>very</u> well. (Shirley2)*

On a longer timescale, participants described learning to recognise how certain behaviours contributed to their illness, and being able to respond differently as a result. Holly, for example, identified how her poor blood sugar management aggravated her condition, and was now monitoring it better. Her account also confirms the role of kindness in motivating positive change:

> *Holly: …instead of ignoring when I'm feeling dizzy and then only taking action when I'm really dizzy, I'm not letting it get to that level, so I'm paying attention to how I'm feeling.*
>
> *JL: So it sounds as though you pick it up much quicker.*
>
> *Holly: And also it's about being kind to yourself, because I don't really know why I was letting it drop so low, except that I didn't really want to get up and get some food. But then I realised by doing that I'm actually causing myself physical stress as well, and changed it. (Holly2)*

7.5.1.4   Able to do more, managing energy better, having something to offer

Whilst some participants highlighted improved energy levels, another important change that many people identified was their ability to manage their limited energy more effectively. As explored previously, people were more 'tuned-in' to and accepting of their needs and less likely to ignore what they were feeling; this avoided previous patterns of *"building up and crashing" (Tania1)*. For some, being able to recognise this pattern and stop sooner reduced the length and severity of their 'crashes', which ultimately meant they were able to get more done than previously, but in a different way:

> *…this is where the pacing I thought came into its own, because you can accept that you can't do much, therefore pace it and actually therefore allow yourself to do more (Rowena1)*

This was a very significant gain for a self-proclaimed "A type" such as Rowena, who had been extremely incapacitated by her illness. Similar themes were evident in the stories of Michaela and Tania, who I considered had some similar personality traits.

As discussed in 7.4b.1.4, other participants also identified being able to do more as a result of their greater awareness of their condition. Jeannette, amongst others, identified how resting in advance of activities enabled her to do things which would otherwise have exhausted and potentially made her unwell. Michaela, whose energy was very limited due to ME, recalled recently choosing to do the family finances, a particularly difficult activity for her, *"at my optimum time for optimum results" (Michaela2)*. She obtained considerable benefit from this mindful approach, both in terms of successfully completing the task and gaining in self-esteem:

That's very powerful actually, it's like it's given me a huge level of control whereas I always felt out of control before around finances. (Michaela2)

On a practical level, Gloria noted that by driving more mindfully, being aware of her speed and acceleration, she had been able to save money on fuel. The use of mindfulness to enable tasks to be done with greater efficiency challenges the commonly-held belief that that it is simply about slowing down and doing less. As Clive noted:

…well because [you're] really concentrated and it's done fast but it's done right'. And it's amazing how fast it can speed things up for you. (Clive2)

Another way that people identified being able to do more was through contributing to the wellbeing of other people. Some participants reflected how their illness had created a situation of dependence, or at least of being more of a recipient than a giver, whether in financial, practical or emotional terms; this had sometimes undermined their self-esteem. As noted previously, practising mindfulness helped people be less critical of themselves and to develop a new sense of identity. In addition however, some particularly valued how it had helped them regain a sense of having something of value to offer. Many described sharing their learning and experience with other people. A few had done this in a structured way, such as by helping on subsequent courses or becoming Breathworks trainers. More often however this process was informal, including lending the CDs and materials to family and friends, or sharing mindfulness techniques and ideas with others. Louise described drawing on her mindfulness skills to support her partner more effectively through a time of crisis, while Sara, who worked in a hospital, identified:

I thought [working] with cancer patients helped people, but I feel like by what I've learned from this course, when I've talked to them about pain and pain management, I've just helped them much more than telling them what drugs to take. (Sara1).

7.5.1.5 Calmer, less driven, more relaxed

Alongside people's ability to achieve more without adversely affecting their health, a very frequently identified change was being able to slow down, take time out and not feel driven to achieve so much. This often had strong links to letting go of previous goals, being less self-critical, and having more ability to appreciate the present moment:

…the more you do it, the more you feel it's relaxing and it's calming, but you don't have to race, and I think the whole thing was my, I've been in a race like all me life and it's, I don't have to live like that. It's the calmness really, it's just a real serene place to be in. (Tania1)

This change affected both everyday activities and longer term life goals and plans. For some, meditation and mindfulness helped them slow them down in a very immediate sense; this seems to have been particularly observed by those experiencing anxiety and agitation. Maya identified that mindfulness for her was *"like stopping, just sort of trying to just breathe and just try and feel a little bit calmer for a moment." (Maya2).* Similarly, Lydia identified how using the meditation to slow down daily activities was important in reducing her stress levels, and also had practical benefits:

> *…funny enough… listening to that always automatically makes me take up the right clothes from the wardrobe. Comfortable clothes, relaxed clothes err, clothes that will keep me for three four hours of comfort not stress. (Lydia2)*

This change in behaviour was not always easy however, as Louise explained, *"I'm not very good when people tell me to slow down, yeah, that is not the direction I want to go in, but it's exactly what I should have been doing, you know?"* (Louise1).

Many people noted feeling generally calmer, having less anxiety and irritation, and being less reactive to stresses in life, as explored in 7.5.1.2. Barbara, who experienced anxiety, found mindfulness tools had given her *"a little safe interior space by just staying in the moment" (Barbara1)* which she found calming. A number of other people used similar language of being more able to create or find a peaceful place. Some obtained a very direct sense of calm and relaxation from doing the meditations, in particular the body-scan. This is an interesting point, as this meditation increases awareness of body sensations, which could be difficult or distressing. The fact that this was not the case may be because those experiences were no longer being struggled with or denied, or because of the focus on the present moment. Certainly, there were many comments about relaxation and calm, which no doubt contributed to changes in people's sleep; this was also seen as creating a healing state for the body. Some noted learning to *"put myself into a relaxed meditative state at the drop of a…" (Michaela1)*. Meditation also helped relieve pain-related tension, partly by creating a time to stop and rest, and partly by diverting attention to other aspects of experience:

> *…when I come back from say doing work and thinking about things then I instantly go to the pain in my head, whereas the body-scan, like if I start with my feet, […], that lets me notice areas in my body which are painful and areas in my body which are not painful, and I think it just also has a general relaxing effect as well… (Helen1)*

7.5.1.6   Clarity and focus

A number of participants observed a definite improvement in their clarity of thinking, which was often connected to their increased calmness. Being less caught up in the stresses of their illness or difficulty enabled people to view their situation and make decisions from a more detached and composed perspective. This helped with day-to-day planning and prioritising:

> *I think it is the concentration of just that, looking in me rather than all the other stuff that's going around and distracting me, and tiring me and maybe thinking, really as in, those things will wait, […] (Leah1)*

Participants experiencing anxiety found they were able to think more clearly about what they needed to do in particular situations. Sue considered that being calmer had helped her think through and negotiate treatment options for her cancer in a clearer way. For participants with memory problems, this clarity was invaluable in helping them manage their lives more effectively. It aided focus and concentration which meant they did not lose things so frequently, and this in turn reduced their stress further. Similarly, Jeannette found that focusing on breathing often helped restore clarity of thinking in instances of "cog fog", the sudden confusion and memory loss associated with a number of conditions. An additional benefit of meditation identified by some people was the mental space it provided in which new insights and perspectives arose; *"almost another dimension"*, as Michaela noted. This seemed to result from being less distracted, and sometimes helped people resolve problems they had been wrestling with.

7.5.1.7 Positivity, optimism, confidence, rediscovering myself

Unsurprisingly, many people felt more positive and optimistic about their lives, with greater confidence to manage the challenges they faced. They could see and value positive aspects of themselves and *"enjoy life again" (Christine, FG)*. They had let go of some of their anxieties about the future, and, in some cases, could look forward to it again:

> *…when I wake up, I want to get up, I'm not thinking "oh no, what am I doing?", it's just made me happy, […] it's made me want to live, and like, I think I've embraced life, I've realised, I think I've realised wallowing doesn't help, but I don't think I'd have got there without the meditation… (Gloria1)*

A number of people described making positive changes in their lives as a result of their improved wellbeing, including pursuing new directions in education, work or relationships. Others had taken up exercise as a result of the mindful movement exercises on the course, having recognised the need to look after themselves in this way; Sue observed, *"one bit of self-care often leads to another" (Sue1)*. These positive actions had direct benefits; Lesley also observed that an indirect benefit of taking on mindfulness practices was feeling she was given greater respect for *"positively doing something"* about her condition, which provided further encouragement.

The greater awareness and understanding of their condition gained through mindfulness provided Angela with greater confidence in negotiating with health professionals:

> *…only a few months ago I was told that I would recover from ME if I started going for a walk every day and kept it up. […] I may a number of years ago have felt so guilty about not going for a walk every day and not putting the effort into going for a walk every day, that I wasn't doing enough to try to recover, and now I just think 'well you obviously don't understand this condition', […] I have enough confidence that is not a cop out on my part, because I know what works and what doesn't… (Angela, FG)*

Some felt that their own positivity and recovered confidence enabled them to offer greater encouragement and support to others who were struggling. For Shirley, who had previously worked in a healing capacity, being able to do this again to some degree was of great importance; she described it as *"coming back to me" (Shirley1)*. This connects with the sense of having something to offer identified in 7.5.1.4. It also highlighted Shirley's

sense of regaining or reconnecting with aspects of herself which she had thought lost. This theme was echoed by others in relation to different abilities and qualities in their lives. In the shorter term, Nadia observed that meditation offered her a way to restore balance when *"there's something in my spirit that's out" (Nadia1)*.

7.5.1.8 Improved relationships, more connection with life and others

Practising mindfulness was seen as having a positive effect on many people's relationships and connections, both to those close to them and to a wider circle of life. In this context, the cultivation of an attitude of kindness towards self and others was particularly highlighted. As was discussed in 7.3.3, this is a core feature of Breathworks, drawing on the Buddhist belief in the interconnectedness of all life, with the kindly awareness practice particularly introduced to cultivate this understanding and awareness.

The willingness to see things from the other person's perspective, and to be less critical and demanding of them, was seen as instrumental in improving a number of significant relationships. A number of participants described being more accepting of others, and more able to observe their behaviour rather than judging or reacting to it and, in some instances, to take it less personally. A greater self-awareness contributed to this, together with the recognition that 'we're all the same' described in 7.3.3. In addition, a few people noted getting satisfaction from being able to offer more kindness to others, and of feeling *"a better person" (Clive2)*.

A number of participants found the kindly awareness practice a useful tool for engaging with difficult or demanding people, including challenging colleagues and family:

> *…she's very difficult to deal with. Very, very over the top, self absorbed, bossy, very bossy, so if I've got to deal with her then I will do a, […] so if it's something, like you know that I can foresee some difficulty […] It means that I can be more sort, I don't know how to put it, more objective if you like more... I can look at it, I can take a step back and look at it, while she's here and not respond to her aggro, yes, not let her wind me up…. (Rosalie2)*

In the context of people's illness, an attitude of understanding and non-judgemental awareness towards themselves and others helped people to better negotiate the stresses that their health problems imposed on their close relationships:

> *I think because I live with pain, […] instead of when I feel pain, sort of stressing out on the pain and taking it out on others, I'm able to take a deep breath, and realise it's not their fault. (Lydia1)*

Whilst remaining aware of their own needs, people were able to recognise the difficulties that others around them experienced. This change had, for some, reduced tension and conflict noticeably and made them *"easier to live with" (Michaela2)*. In addition, as noted previously, participants were less fearful and more open in communicating about their illness experience and needs, and able to ask for and accept help. This helped others respond more appropriately, which in turn often further improved relationships:

> *…it helps them understand a bit more about you than if you pretend you can always do things when actually you can't really. (Holly2)*

On a wider scale, openness and acceptance of the whole of experience sometimes created a sense of profound connectedness, as in Michaela's description of meditation:

> *It's good. It's timeless. I lose all sense of time, I can lose all sense of space as well, all sense of, I can feel this just a huge connection with like all of mankind whatever it is that I'm doing, and I like, touch base with me and touching base with me and my heart if you like, what really matters, at the same time I'm touching base with everybody around me and what really matters in life. All sounds a bit sort of airy fairy and bit sort of guru maharaji-ish, I can't explain it really… (Michaela2)*

Others observed how recognition of a shared humanity reduced their fear of people, or allowed them to create and appreciate moments of contact or conversation in new ways. It also offered something which took them out of the isolation created by illness and created a *"really lovely feeling" (Rosalie2)* of connection with others across the world. Drawing on the practice of seeking the pleasant, a few people also described being able to connect more deeply with nature:

> *… I just get this thing that I think, 'oh just sit so this is a beautiful moment', it's like, it like when the camera lens has been hazy for a long time and then all of a sudden like you are in this beautiful, in this beautiful scenery in front of you and water and sun and sky and beautiful greenery around, but it's all been hazy before and it feels like there is clarity, it feels like I can see it all for the beauty that it is, and I don't really think I have ever had time to take it all in before. (Tania2)*

Such moments of what could be termed 'spirituality' did not happen all the time, but could sometimes unexpectedly arise in people's lives. These appeared to be identified mostly by participants who had engaged deeply with the mindfulness practices, and had been or were regular meditators. It may be that these experiences are more likely to happen in these circumstances, where more profound changes in perspective, and indeed in brain structure, may have taken place.

7.5.1.9 Better quality and balance of life, changed priorities

Many of the changes and benefits presented above could be termed improvements in the quality of life, and this term was mentioned in some way by most participants. Improvements in symptoms and coping abilities, being able to live life more fully, experiencing greater wellbeing and connection all contributed to participants' experience of being *"more content now than I've been for years, absolutely years" (Tania2)*. As Louise jokingly remarked, *"My life suits me - don't tell anyone how good it is!" (Louise1)*. People felt able to live well with their illness, and that mindfulness offered:

> *…a very good strategy to help you live a full life irrespective of whether you have still got the symptoms or not […], accepting that that is, you know the symptoms are there or you might feel rubbish but there are still things you can do. (Holly2)*

In addition, many people felt their priorities had changed and that the balance of their life was now different. Many no longer aspired to the life they had before, recognising how in in some cases this had contributed to their illness:

> *…I'd actually faced up to what the barriers were to getting back to being what I was, which was what I was desperately trying to do. And the realisation that it was the way I was that had got me into the state that I was in, and did I really want to go back to that?, and once I had accepted it […] then I could get on with life as it never was. (Christine, FG)*

For many, this change had not come without a struggle, but had allowed them to value *"the simple things"*, including everyday experiences and relationships rather than achievements in work or at home. This appreciation was often facilitated by changed life patterns, with many people being less caught up in their previous busy life; however, it also came from a changed perspective, which meant they were less overwhelmed by their illness.

As explored in 7.5.1.7, a changed sense of priorities had led some to take new directions in life more in keeping with their values. This, for a very few, connected with some sense of higher purpose in life such as Gloria's perspective that:

> *…I think I should've died and I didn't die 'cos I was meant to do something completely different… (Gloria1)*

Gloria identified as a Catholic, and was the only person to be explicit about there being some purpose and meaning behind her illness, although a few people from both Christian and Buddhist traditions commented on things being 'meant to be' in relation to aspects of their lives. I found the relative absence of this perspective striking, as it is one that has quite wide currency, at least in circles in which I move. This probably reflects the fact that the Buddhist tradition on which Breathworks draws teaches an acceptance of life <u>as it is</u>, rather than seeking to give experiences meaning, either positive or negative, as a way of understanding and managing them. This perspective of acceptance is more dominant in the data, as encapsulated in Shirley's observation:

> *I know I can't ever be that woman who did what she was doing before all this began, but I'm making a fair job of my life and enjoying it. (Shirley1)*

7.5.1.10   No negative outcomes

Participants made no reference to any negative reactions or outcomes from mindfulness or the meditations although, as noted previously, one participant found greater awareness of her experience unhelpfully painful. This subject was not directly explored with many participants, but the response in the focus group was clear:

> *JL: … nobody's ever found that it's made their pain more difficult to live with or increased stress?*
>
> *?:   No definitely not*
>
> *?:   Absolutely not*
>
> *[general agreement that this is not the case]*

Other participants echoed this sentiment: practising mindfulness could be challenging, but the outcome had never been perceived as damaging or detrimental.

7.5.2 Identifying benefits for others

Although the primary benefits were clearly to individual participants, a number also identified that others around them had benefitted either directly or indirectly from the changes in their own life. A number of areas were identified and will now be outlined.

7.5.2.1   Less worried about me, understand and know how to help

The benefits most frequently referred to concerned how changes in the participant's condition and/or ways of coping with it had improved the situation for family and friends in various ways. Participants were often aware of the demands their illness had created on those around them, and some described their relief that these demands were no longer so great. In a few cases improvements in people's condition meant they needed less practical help. More commonly, they were aware that changes in their overall wellbeing meant others felt less anxious or concerned about them, knowing they were suffering less and coping better. This created further indirect benefit for the participant:

> *…at the time I was worried that I was upsetting my children by being so anxious, so there was a secondary benefit which was nice because they've commented on it... (Barbara1)*

The other significant change resulted from participants' greater ability or willingness to communicate about their condition. This enabled those around them, particularly close family, to understand what the person was experiencing and respond appropriately, rather than trying to 'second guess' what might be needed. This included suggesting the participant took time to meditate, knowing that they found this helpful, or noticing they needed to take some medication as a result of being more aware of the signals that they were in pain. Improved communication led to reduced tension, and probably enabled others to feel less helpless in supporting someone they cared about.

In a variation on this pattern, for one participant whose partner was now learning mindfulness practices due to his own health crisis, a shared knowledge of the tools and language of mindfulness gave her ways to support <u>him</u> more effectively, thus benefitting them both.

7.5.2.2   Improved relationships: I'm easier to be with, more available

Participants also saw how changes in their mood and attitudes had had wider effects on their relationships. They were calmer, more patient, less irritable and anxious, and less reactive and critical and, as a result, others found them *"easier I think to be around" (Michaela1).* Mirroring the benefits they identified for themselves in 7.5.1.8, this for some had led to fewer conflicts and produced a change in others' behaviour. For example Nell identified a change in her whole relationship with her mother:

> *…if I'm better she's better, and if she's better I'm better. You know so we're not at each others' throats. Cos we have had some bust ups. A lot better. (Nell2).*

Shirley reflected on how her family and friends had always valued her support and inspiration, and had been shaken by its loss when her illness dominated her life. Being more available to them again was therefore greatly appreciated. She also observed how seeing her *"get through stuff" (Shirley2)* had helped encourage others in their own

struggles. This was echoed by John, who commented how people had been inspired by his way of managing cancer. Being able "*to make that difference" (John2)* in turn provided the participants with a sense of having something to offer, as described in 7.5.1.4.

7.5.2.3 Developed or improved their own mindfulness practice

Participants also observed how their engagement with mindfulness had sometimes directly led to other people taking up or developing their own mindfulness practice. This included family, friends and in one case a health professional with whom a participant had close contact. A number had attended Breathworks or TBC courses as a result, whilst Lesley recalled taking the learning from the course back to her existing Buddhist group and seeing how this had improved others members' meditation practice.

7.5.3 Degrees and patterns of change

Whilst participants identified many changes in their experience, they also observed varying degrees of benefit and patterns of change. A few also mentioned limitations or lack of benefit from practising mindfulness. These points will now be explored.

7.5.3.1 Degrees of change: it changed my life, it made no difference

> *Well, it's a bit dramatic but I think something that's quite important is I think I probably would have killed myself if I hadn't gone to Breathworks, because the point leading up to the first course I had felt very suicidal, and, but just the fact that I was having something there I think kind of diverted me from that, I mean I don't know, but obviously that's quite a big thing! (Helen1)*

Helen's statement illustrates the profound level of change some people experienced as a result of learning and practising mindfulness. She was not the only participant who identified this degree of desperation prior to the course; a few people mentioned having suicidal thoughts due to their level of suffering, and a number noted that it had been 'a life-saver'. For many others, the experience had *"significantly changed my life, yeah, and I know quite a lot of us feel that…" (Rosalie1)*. They recognised that mindfulness *"does me so, so much good" (Michael2)* and, looking back, could see how much they had changed and improved since attending the course. A number of people echoed Louise's comment that *"I can't imagine not having it." (Louise2)*, illustrating the important place it had within their lives.

Comments indicating such a significant degree of change were made by more than half the participants. In contrast, whilst almost all the other participants identified some degree of positive change, they did not describe it in the way explored above. In most instances, this was due to the absence of any comment, rather than a more qualified statement about the change experienced, and at least some of these participants identified a number of benefits from mindfulness. A few noted seeing only partial or temporary changes, such as short-term relief of symptoms, or improvements in mood rather than in pain levels; however some of these people also observed that mindfulness had changed their lives. Others identified that they had only integrated mindfulness into their lives to a limited degree: *"I've got a way to go yet" (Wendy2)*; they had therefore not seen such comprehensive changes in their outlook and ways of living.

As noted in 7.4a.2.1, only two participants made direct reference to not finding benefit from mindfulness practice. Susanne, whose interview did not take place, referred to her inability to use mindfulness around her distressing symptoms and treatment, finding greater awareness of her experience unhelpful or unbearable. No further information was obtained from her, and it is therefore not possible to know whether there were other dimensions to her experience. The other participant, Robert, presented a more complex picture, as this extract suggests:

> J: *…and in terms of how you were managing your pain, did you feel there was any benefit for you?*
>
> R: *No. I didn't. At the time, and looking back, I don't think it had any effect on the pain management at all. Err, but I do think it had a positive effect on me. Yeah? But that's not the same thing at all. (Robert1)*

On further exploration of what he had hoped to gain from Breathworks and mindfulness, Robert stressed that he was aware it would not cure his pain, but *"thought it might just be beneficial to me, to my life".* As he was unsure whether it had been helpful, he was equivocal about recommending the course to others, although he had enjoyed it and found it interesting. Robert described continuing to practice relaxation, and adapting some of his existing self-hypnosis techniques in the light of learning mindfulness. He did not however see any value in further contact with Breathworks, not considering this would be beneficial in terms of pain management; however it was not possible to identify what form this benefit might have taken.

Strikingly, during the interview Robert identified a number of changes which closely reflected those described by other participants as key benefits of practising mindfulness. These included: greater appreciation of present moment experience; living with and managing the pain better; a more understanding and accepting relationship with pain; and feeling more relaxed and calm. The process of the interview seemed to enable Robert to identify some of these changes, but he was not convinced they were directly linked to the course, considering this could be coincidence or the result of other changes in life. He was interested to note these changes, but they did not alter his perception that the course had not helped his pain management. This is in very clear contrast to other participants who directly attributed similar experiences to their mindfulness practice. Clearly, the course did not meet Robert's hopes and expectations, which perhaps meant that the benefits it could offer were not recognised, as they did not correspond to his current needs. This lends support to the idea of 'readiness' discussed in 7.4a.1, which was explored further in the trainers' focus group.

7.5.3.2   Patterns of change: immediate benefit, cumulative effect

Just as the degree of change varied, participants also noted variation in how change took place, which predominantly related to differences in timescale of response. For a significant number of people, change was observed very soon after embarking on the course and starting to practise mindfulness. In some instances there was an observable change in aspects of their symptoms, stress levels and sense of wellbeing *"pretty, pretty soon, straight away almost" (Rosalie1)* or after only a few weeks of attendance. Rapid change was also noted in terms of an immediate response to meditation:

> *…I found the body-scan, or <u>do</u> find the body-scan unbelievable, […] when you get into a moment that you, you are not able to cope with, normally I would just whizz off or, but while I've been using the body-scan and I've been using it now for near enough six years I think, everything just sort of, I don't feel the same person after the body-scan as before it, I feel <u>completely</u> replenished as though I've been changed from top to toe. (Paula, FG)*

Similar changes in pain, mood or energy levels were identified by a number of people, and contributed to their sense of being more able to cope with their symptoms, knowing they could obtain at least temporary relief.   These immediate effects could sometimes be achieved with very short periods of mindfulness, such as the 'three minute breathing space', whose value was often referred to: *"it's amazing what that can do" (Hannah1).* Becoming mindful of their breathing during a stressful situation also enabled a number of people to change their state of mind and respond differently.   This was particularly mentioned by people with a regular meditation practice, who were therefore 'dropping back' into a familiar pattern and experience, as well as perhaps being less stressed in the first place.

The cumulative effects of meditation and mindfulness were noted by a number of people, contrasting with or sometimes complementing the immediate changes identified above. Regular practice was seen by many to deepen meditation experiences, as well as increase and extend the benefits into the rest of life:

> *The meditation did get better. Me getting into the meditation got better. As you practice more it had a bigger impact on me the more I did it, feelings lasted longer afterwards, my ability to cope with my illness and life improved and it just, everything improved. (Tania1)*

As explored in 7.4a.3.3, some people found regular meditation practice to be initially necessary to build a 'critical mass' of change, but then maintained this with less frequent practice combined with 'everyday mindfulness'.

A number of people observed that practising mindfulness over a period of time had allowed them to recognise that *"sometimes it just doesn't work" (Rosalie2)*; thus, individual meditations did not always produce a change, or only to a limited degree. One participant also noted that it had taken her some years to be ready to benefit from a particular meditation practice. As explored in 7.4a.2.1, participants accepted these limitations and understood the need for on-going engagement with mindfulness practice. As highlighted in 7.4a.2.2, this commitment was supported by the positive and often profound changes they had seen over time, in some cases many years. They developed a *"progressive trust […] in that it works a bit, so you trust it a bit, it works a bit more so you trust it a bit more" (Michael1).*   The fact that these changes continued to happen gave participants further encouragement and an optimism that this process would continue.

7.5.4   Summary of theme: seeing a change

Participants identified nine key areas of personal benefit from practising mindfulness, including positive changes in actual symptoms and many other areas of life. People were more able to cope with the challenges in their lives, and to manage their condition in ways that reduced its impact and enabled them to live more fully. They experienced improved

emotional wellbeing and mental clarity, greater calmness and relaxation, and less need to push themselves. Many identified having a better quality of life than before their illness, although this was balanced against the recognition that these gains had come at a high price, and they would still prefer to return to health. Having recognised this was not within their control however, they felt more positive and confident about themselves. Their relationships with those around them were also often significantly improved, giving a greater sense of connection with the world.   Patterns and degrees of change ranged from life-changing transformations to no identified benefit. Differences in the speed of change were also noted, some seeing rapid benefit whilst others described a more gradual, cumulative process.

Although not everyone identified all nine areas of benefit, the majority were mentioned by most interview participants and in the focus group discussion. All but three benefits were mentioned by at least 20 interview participants and by the focus group, whilst 19 interview participants and the focus group mentioned at least seven of the areas of benefit. It is interesting to note that some participants who identified very powerful and significant changes did not refer to as wide a range of benefits, perhaps having focused their conversation on specific aspects of experience. In contrast, Robert, who did not consider that mindfulness had made any difference, made reference to six of the nine areas. These numbers therefore only offer an indication of how strongly the themes are reflected in the data, and do not fully represent the complexity of people's experiences.

Whilst less often referred to, participants also saw a positive impact on those around them. Improved communication had helped family and friends to understand participants' needs and to help more effectively, thus reducing their sense of helplessness and frustration. Seeing positive changes in the person also reduced anxiety in those close to them, as well as offering inspiration on occasions. Participants considered that they were 'easier to live with' and more open to those around them.   Other people had also sometimes been motivated to develop their own mindfulness practice, which gave participants a sense of having something valuable to offer. Participants were often aware of the significant impact their illness had had on others, and they thus welcomed these benefits. The benefits for self and others were thus mutually reinforcing, and enhanced people's overall sense of seeing a change from practising mindfulness.

7.6   Chapter summary and connecting the themes

In this chapter, the core process of *'Starting where I am'* has been identified, together with five themes: *Getting a new perspective; Feeling equipped to cope; Doing life differently; Seeing a change* and *Finding it difficult*. *'Starting where I am'* captures the essence of how practising mindfulness allowed people to become aware of and accept their situation, and respond appropriately to it.   It represents the experience of finding a way to cope with an unwanted journey to an unfamiliar place, which is the metaphor I have used to describe the challenges of living with a LTC. Aspects of this experience and process are expressed through the five themes. Each theme, and its relationship to the core process, has been explored. In this concluding section the interrelationships between the themes and how

they contribute to the core process is examined more fully. To aid this, the model presented at the start of this chapter is reproduced in Figure 7.9.

Figure 7.9 Relationships between key themes and core process
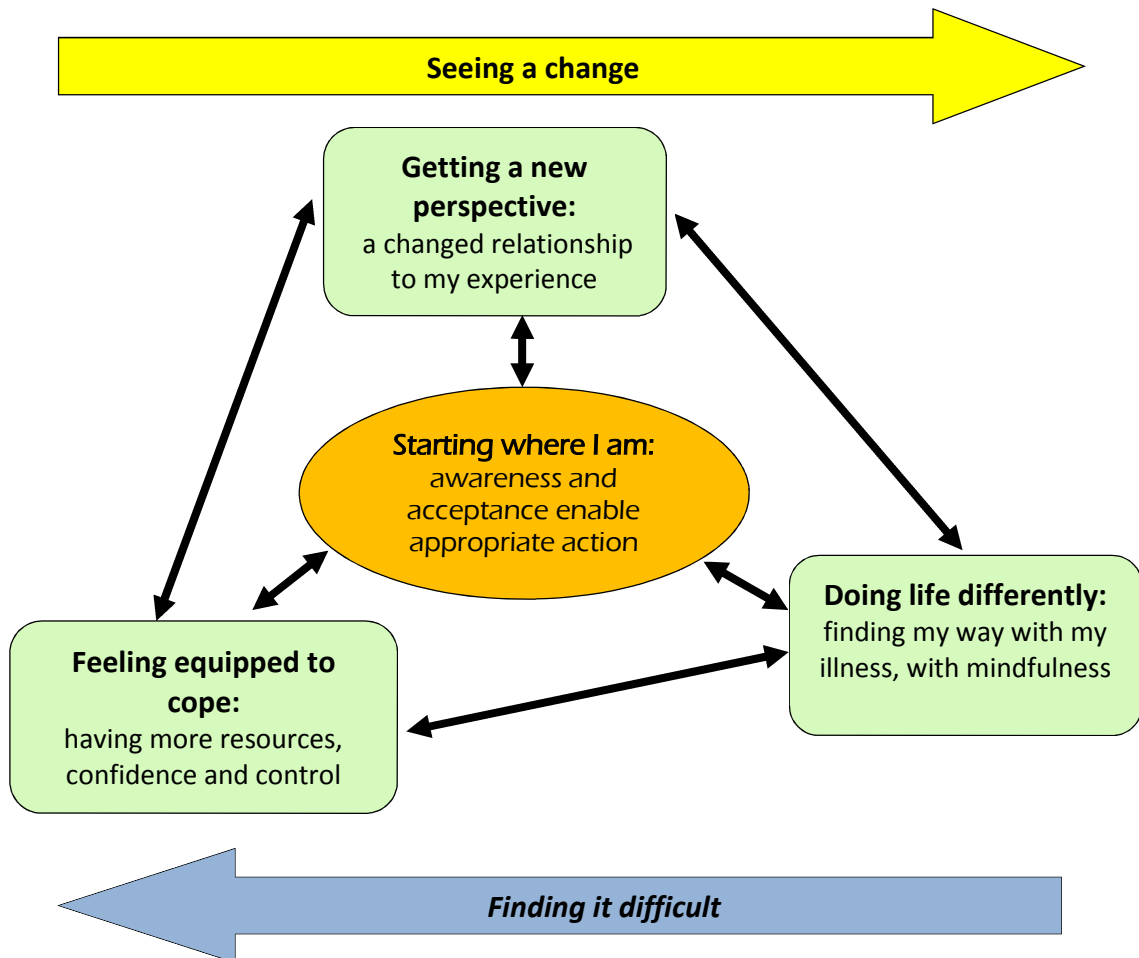
Throughout the interviews and focus group, participants recounted in detail how practising mindfulness had affected how they lived with and managed their condition *(Doing life differently: Finding my way with my illness)*. They identified being able to *'start where I am'* and take action in response to their symptoms, both in the immediate and longer term. For many people, their behaviour was significantly different from before learning mindfulness, as they now took more account of their own needs and limits and were kinder to themselves.

Mindfulness enabled participants to see and understand their illness clearly, and how it affected them, but also to remain aware of the broader context of their lives *(Getting a new perspective: a changed relationship to my experience)*. They were brought into greater contact with difficult aspects of their experience, but also gained more awareness of its positive aspects. Focusing on present moment also took people's attention and energy away from distressing thoughts and feelings about the past or future. It helped them to see more clearly what was actually happening at that time, rather than

catastrophising or ruminating on their experience: *"just to come back to where I am really"* *(Kathy, FG)*. By having more perspective on their illness, as well as a clearer awareness and acceptance of it, they could *'start where they were'* and make more accurate and informed decisions about managing their condition *(Doing life differently: Finding my way with my illness)*. This is explored in the memo extract in Figure 7.10.

Figure 7.10 Extract from 'Starting where you are' memo

> *The point about this is that it is the place you're in, so trying to start from anywhere else is not going to get you where you want to go anyway, because at some point your map is simply not going to match what is happening to you on the ground, and that's going to get you into trouble of some kind [….] If you aren't looking at the place you're actually in, then in a sense it's going to be more difficult to get out because you haven't got accurate information to work with.*　　　　　　　　　　　　　　　　　　　　　　　　　　　*(1/3/13)*

Changes in perspective made it possible for people to tolerate paying more attention to their illness*,* recognising that it was only a part of their experience, often a smaller part than imagined, and that it was also in constant change. It increased people's confidence that that could *'start where they were'* and face and accept any future challenges, such as changes in their condition *(Feeling equipped to cope: having more resources, confidence and control).*   As a result they felt less identified with and overwhelmed by their illness, which enabled them to see themselves differently *(Getting a new perspective)*.

Practising mindfulness was however not always easy *(Finding it difficult)*. It required behaviour change, which could be challenging, both to the individual and to those around them. It involved changes in attitude and, in particular, a movement towards greater awareness and acceptance of their health condition *(Getting a new perspective),* which was sometimes difficult and painful to do. To undertake such changes therefore required a number of elements to be in place, including motivation, skills, resources and support. Participants identified how Breathworks had provided these elements *(Feeling equipped to cope)*, making it possible for them to engage with mindfulness practice and *'start where they were'.* They learned practical techniques and gained new ways of understanding their experience. They were inspired by seeing the trainers managing their own conditions with mindfulness, and experienced a sense of connection to others struggling on their illness journey. These tools and experiences motivated and enabled participants to take what they had learned and integrate it into their lives in ways that met their needs *(Doing life differently: Finding my way with mindfulness)*.

Through practising mindfulness, participants saw many benefits in their lives and in those around them *(Seeing a change)*. This gave them a new sense of confidence and control *(Feeling equipped to cope)*. The more they practised mindfulness, the greater their sense of competence, which added to their motivation to continue *(Doing life differently)* in order to maintain and develop these beneficial effects.

As can be seen, the themes in this process are closely connected, and it was this complexity of experience which enabled people to change how they related to and managed their conditions, to *'start where they were'*. For some, these changes profoundly

transformed their experience, for others much less so. The variation in the degree of change and the reasons for this were clearly complex. I was keen to explore this issue further, and the trainers' focus group provided a valuable opportunity to do this, and to consider a number of other questions arising from the analysis. These included the role of different elements of the Breathworks programme in the process of change, particularly the contributions of formal meditation and informal mindfulness practice; and the relationship of kindness to mindfulness. The next chapter identifies the additional insights, and confirmation of existing themes, that the trainers' focus group provided.

Chapter 8
Trainers' focus group findings

8.1 Introduction

The Breathworks' trainers' focus group formed the last stage of data collection. As noted in 6.3.2, the majority of the trainers were living with long-term conditions (LTCs) and all had a regular mindfulness meditation practice. The focus group explored a number of specific questions identified through analysis of the interviews, and the findings in this chapter therefore focus around these particular areas of enquiry. To a large extent, the findings from this focus group were consistent with and developed the previous analysis; this was unsurprising given the nature of the questions and the composition of the group. This chapter is therefore structured around the themes identified in chapter 7, with both confirmatory and additional material being integrated and discussed in relation to them and the core process. Figure 8.1 presents the themes and categories from the previous chapter, together with the changes made as a result of the analysis of the focus group. Text in red indicates aspects of the analysis supported by the trainers' discussion; new dimensions are shown by text highlighted in yellow. New categories are numbered to correspond with the existing structure, but indicated by an 8. In the exploration which follows, findings are cross-referenced where possible to relevant sections of chapter 7.

8.2 Getting a new perspective: a changed relationship to my experience

Whilst not a focus of the discussion, the trainers' comments confirmed many aspects of this theme, but did not add significantly to it. Many had first-hand experience of learning to *'start where they were'* and accept and move towards their pain or illness (7.2.1). They echoed observations made in the previous chapter about how this change in perspective had affected their experience of their condition (7.2). Josie's comment illustrated this, and also confirmed the value of focusing on process rather than outcome (7.4b.3)

> *I don't think the course is about pain, I think it's about living and that's the difference, because you have the pain whether or not, it's whether you are going to live with the pain and stay in the pain and not have any life, or whether you want to accept the pain and have some life round it, […] it's a relationship you have with something that you can't do anything about. (Josie)*

Figure 8.1 Additions to and confirmation of the analysis from trainers' focus group

Theme	Category	Sub-categories		
7.2 Getting a new perspective: a changed relationship to my experience	7.2.1 Moving closer to difficulty: facing up to and accepting how things are	7.2.1.1	Letting go of trying to fight, deny, solve the problem: accepting, facing reality	
		7.2.1.2	Allowing myself to acknowledge my difficult situation	
		7.2.1.3	Finding it possible to move on	
		7.2.1.4	*Finding it difficult: struggling to accept, move towards suffering;* balancing acceptance and change	
	7.2.2 Stepping back, seeing the bigger picture	7.2.2.1	Appreciating what's good, looking for the positive	
		7.2.2.2	Keeping aware of the whole of my experience	
		7.2.2.3	Recognising that experience keeps changing	
	7.2.3 Focusing on the present moment	7.2.3.1	Letting go of the past and future	
		7.2.3.2	Stopping trains of thought, catastrophising	
		7.2.3.3	Using mindfulness to distract myself from difficulty	
	7.2.4 Finding a new sense of identity	7.2.4.1	Letting go of old identity and beliefs	
		7.2.4.2	Acknowledging but not identifying with my thoughts and illness	
7.3 Feeling equipped to cope: having more resources, confidence & control	7.3.1 Having a range of accessible tools and skills I can use in everyday life	7.3.1.1	Having a structure, permission, something to do	
	7.3.2 Having new ways to understand and talk about my experience			
	7.3.3 Feeling supported, connected, less isolated	7.3.3.1	*Finding it difficult: not feeling part of the group*	
	7.3.4 Gaining confidence and competence in managing my condition	7.3.4.1	Seeing it's possible to live well with illness, ==to practise mindfulness==	
		7.3.4.2	Discovering, feeling confident mindfulness can help	
		7.3.4.3	Feeling competent, able to do something for myself	
	7.3.5 Having more control and choice in my life, responding not reacting			
	7.3.6 Knowing and understanding myself better			

Theme	Category	Sub-categories	
7.4 **Doing life differently: finding my way with my illness, with mindfulness** 7.4a Finding my way with mindfulness	7.4a.1 Getting started	7.4a.1.1	Attitudes and perceptions help *or hinder*, readiness is important
		7.4a.1.2	Positive course experiences
		7.4a.1.3	*Finding it difficult: challenging course experiences*
		8.4a.1.1	Engaging with mindfulness in severe illness: *finding it difficult*, finding it possible
	7.4a.2 Taking it on, keeping at it, finding ways to maintain practice	7.4a.2.1	Making time, making a commitment
		7.4a.2.2	Motivated by seeing a change
		7.4a.2.3	Making mindfulness a way of life, finding it becomes second nature
		7.4a.2.4	*Finding it difficult: struggling to establish and maintain practice*
		7.4a.2.5	Finding strategies to support practice
		7.4a.2.6	Research participation as a support to practice
	7.4a.3 Making it my own, developing patterns of practice	7.4a.3.1	Patterns: practising regularly or responding to need
		7.4a.3.2	Patterns: balancing formal and informal mindfulness practice
		7.4a.3.3	Patterns: practice changes over time
		7.4a.3.4	Choices: selecting what works best for me
		7.4a.3.5	Choices: integrating or replacing mindfulness with other tools
		7.4a.3.6	Choices: adapting practices to my own needs
		8.4a.3.1	Supporting people in 'making it my own'
		8.4a.3.2	Adapting mindfulness practices and ideas to meet people's needs
		8.4a.3.3	Exploring the role of meditation within mindfulness practice
7.4b Finding my way with my illness	7.4b.1 Aware of and responding accurately and appropriately to my needs	7.4b.1.1	Can monitor self, symptoms and respond more quickly, accurately
		7.4b.1.2	Can plan what to do to manage condition, meet needs
		7.4b.1.3	Can make informed choices and decisions about how to live life
		7.4b.1.4	Recognising I can do more, challenging myself, choosing to push my limits
		7.4b.1.5	Stopping sooner, not ignoring my needs, avoiding flare-ups
		7.4b.1.6	*Finding it difficult: Becoming aware of not being mindful*
		8.4b.1.1	Demonstrating mindfulness in action

Theme	Category	Sub-categories
7.4b Finding my way with my illness ctd..	7.4b.2 Becoming kinder to myself	7.4b.2.1 Not judging myself as much, appreciating myself and what I can do 7.4b.2.2 Looking after myself better, putting myself first 7.4b.2.3 Being open with others about my condition and needs *7.4b.2.4 Finding it difficult: struggling to be kind to myself, put myself first* 7.4b.2.5 Identifying <mark>and emphasising</mark> the role of kindness
	7.4b.3 Focusing on process rather than outcomes	
7.5 **Seeing a change**	7.5.1 Identifying benefits for self	7.5.1.1 Seeing symptoms improve or stabilise 7.5.1.2 Coping better with difficult situations, including symptoms 7.5.1.3 Avoiding illness-related problems 7.5.1.4 Able to do more, managing energy better, having something to offer 7.5.1.5 Calmer, less driven, more relaxed 7.5.1.6 Clarity and focus 7.5.1.7 Positivity, optimism, confidence, rediscovering myself 7.5.1.8 Improved relationships, more connection with life and others 7.5.1.9 Better quality and balance of life, changed priorities 7.5.1.10 No negative outcomes
	7.5.2 Identifying benefits for others	7.5.2.1 Less worried about me, understand and know how to help 7.5.2.2 Improved relationships: I'm easier to be with, have more to offer, <mark>more aware of others' needs</mark> 7.5.2.3 Developed or improved their own mindfulness practice <mark>8.5.2.1 New resources and perspectives for health professionals</mark>
	7.5.3 Degrees and patterns of change	7.5.3.1 Degrees of change: it changed my life, it made no difference 7.5.3.2 Patterns of change: immediate benefit, cumulative effect

Key: Text in red indicates themes, categories and sub-categories confirmed by the discussion

<mark>Text highlighted in yellow indicates new sub-categories resulting from analysis of the focus group</mark>

Participants recounted developing greater awareness and understanding of themselves. Illustrating the interaction between the themes delineated in 7.6, Josie described the subtle relationship between discovering she was able to do more than she thought (7.4b.1.4) and changing her beliefs about herself (7.2.4.1):

…you have to give yourself permission to get better, I've done the mindful movement course, was teaching it, couldn't put me trousers on because in me head I still couldn't put me trousers and […] when I actually realised what I was doing, nobody could have put me trousers on, an athlete couldn't put me trousers on the way I was holding them but it was just that I was so sure that I couldn't do it, because I had not done it for so long […] so it's actually acknowledging that you can do things that you couldn't do before.

Josie also highlighted another way that mindfulness enabled a move towards a more accurate self-perception. She observed that people with illness *"want to go back to the day before the pain began"*, and can remain attached to that image of themselves even many years later, when in fact ageing or other life events mean they would no longer be that person, regardless of the illness. Mindfulness allowed people to move on from this old identity (7.2.4.1) and appreciate the positive aspects of their present moment experience (7.2.2.1).

8.3   Feeling equipped to cope: having more resources, confidence and control

As with the previous theme, this area of the analysis was not explored in any depth, although aspects of it were confirmed during the course of the discussion. The most notable addition was in relation to the observations made by participants in the previous chapter, who frequently commented on the inspiring examples the trainers provided of living well with their condition. The trainers recounted many experiences of working with mindfulness and meditation and, as is discussed further in 8.4b.1, it was clear from their behaviour in the meeting that they 'practised what they preached'. During the discussion they acknowledged the importance to many participants of the example that they provided. Developing this topic further, they noted how other course participants *"who had gone further down the road of acceptance"* also provided motivation to those who were still struggling *"to beat this, […] to get back to where I was" (Harriet)* by demonstrating a different way of living with illness.

Another notable element of the trainers' behaviour, which I had experienced when attending the course, was their willingness to share their own challenges with practising mindfulness. Valerie commented that *"meditation is basically quite demanding, so if you can get away with not doing it you are not going to do it"*. Other participants recounted their struggles with practice, and how they continued to use the Breathworks tools to support them. This honesty and openness about the challenges of mindfulness and meditation, as well as strategies for overcoming them, may offer helpful inspiration to participants, and confirm the feeling that 'we're all the same', thus reducing isolation (7.3.3). In addition, particularly when participants are getting started with practice, they may be reassured by knowing that finding mindfulness practice difficult does not prevent

people from benefiting from it. This additional aspect is reflected in a slight amendment to the sub-category referring to the inspiration the trainers provided to participants (7.3.4.1).

8.4 Doing life differently: finding my way with my illness, with mindfulness

8.4a Finding my way with mindfulness

8.4a.1 Getting started, taking it on

As noted at the end of the previous chapter, I was interested to explore with the trainers why some people seemed to engage with and benefit from mindfulness more than others, and what factors affected this variation. Between them, the focus group members had many years' experience of observing people's participation in Breathworks, and were therefore in a unique position to comment on this question. Their answers confirmed many of the ideas explored in the previous chapter, and added some new perspectives, as will now be discussed.

In relation to getting started with practice (7.4a.1), the importance of people's attitudes was emphasised, including the idea of 'readiness'. This idea had been explored previously, and its prominence within the discussion led to it being added to the sub-category's title (7.4a.1.1). A number of trainers commented that acceptance and willingness to *"in some way to let themselves be aware of their suffering" (Ursula)* were pivotal to being able to engage with what Breathworks were offering. They noted that people needed to be open to trying something different, either because they were naturally disposed to this, or as a result of having worked through other options to improve their health. Timing of people's attendance in relation to their journey with their illness was therefore significant; the trainers observed how this sometimes prompted participants to attend the course more than once:

> *…I think I plant the seeds and when the person's ready to use those seeds or they are ready to germinate, well they come back and find out more… (Josie)*

As observed previously, a willingness to take responsibility for their health and make changes in their behaviour were also stressed as important:

> *…if we get people coming on the course thinking […] you are going to meet these nice people who will take your pain away and actually get the message 'well no, mindfulness is about being in direct relationship with your experience and transforming how you relate to it', that's a much more challenging message. (Valerie)*

This again emphasises the centrality of acceptance and facing the difficulty of one's situation to the core process of '*Starting where I am*', as explored in 7.2.1. The trainers recognised the challenge this presented (7.2.1.4), and highlighted various ways the course supported participants in to undertake this change of perspective. The role of the group was emphasized; building trust and confidence was seen as key to supporting people's

engagement with mindfulness practice (7.3.3), whilst sharing positive experiences provided motivation to try activities that may not initially have been seen as helpful (7.4a.2.2).

Additional factors highlighted by the trainers as potentially important to people's motivation were whether they were self-funding or referred, and whether they came as a result of a personal referral rather than a general enquiry. In the former case, higher levels of drop-out were noted in a group which formed part of a research project, possibly due to less sense of personal responsibility and commitment. Participants may also have been less likely to be 'ready', having not gone through the same set of decisions to attend the course. In the latter case, personal referral might contribute in a variety of ways: the referrer could have made an accurate assessment of the person's likelihood of benefitting, whilst the participant may also have a clearer understanding of and confidence in the course and be motivated by having seen or heard how someone else had benefited.

In addition to these attitudinal factors, I specifically asked the group to consider whether the nature or severity of people's illness affected their ability to engage with mindfulness. I was particularly interested to explore this, given the participant's experience described in 7.2.1.4 of finding it unhelpful to move towards her suffering. Some trainers suggested that people with primarily mental or emotional suffering could on occasions find the process more difficult to engage with, either as a result of being in a minority within the group (7.3.3.1), or finding some of the concepts less applicable to their experience (7.4a.2.4). This was however a minority view; most trainers emphasised how *"a bit of tweaking" (Claire)* enabled mixed groups to operate successfully.   This approach confirmed participants' accounts of the trainers' flexibility (7.4a.1.2) and of finding that after some initial discomfort, the specifics of their condition were either taken account of or ceased to be relevant.

Considering whether certain types of conditions or degrees of suffering were not amenable to mindfulness, trainers shared experiences, both personal and of those they had trained, of people in extreme levels of physical and mental distress gaining benefits from the course and practising mindfulness. This included someone with PTSD in great physical pain who was *"supping the morphine as the session went on" (Harriet),* and considered the course had changed her life, going on to attend it a second time. One of the trainers recounted her own experience of receiving diagnosis of a terminal illness during her training and how mindfulness enabled her to:

> *…concentrate and think 'I am coping at this moment', and as long as you stop in that moment you are okay, there is no point in worrying about anything else is there? (Josie)*

Clearly in these instances the process of mindfulness and the experience of the course provided powerful tools to help people cope with extremely difficult circumstances.

In contrast, the trainers also recognised instances where participants had been in too great a level of distress to benefit from the course. On most occasions this seemed to relate to mental health problems, where high levels of depression or anxiety had prevented people engaging with activities. Difficulties were particularly identified in relation to anxiety, where participants had been unable to sit still for any length of time or found that trying to do the meditations and other practices aggravated their anxiety. These observations

mirror Maya's account of struggling with the meditations due to her agitation and anxiety (7.4a.2.4). Valerie also recalled a participant in extreme physical pain and mental distress who *"would have said 'I can't bear my pain, I can't get close to it'"* and *"wasn't coping",* but noted that despite this she attempted to do the course three times. Ursula observed that a person's ability to function in their life was often a better indicator of their ability to benefit from the training than the particular condition they were living with.

Overall, the trainers considered that most people were potentially able to benefit, and their willingness to support those experiencing extreme difficulties reflects Rowena's observation that:

> *…they were absolutely committed and they had absolute faith in what they were doing, because they weren't just creaming off the people who were kind of marginally, the easy ones to put right. (Rowena1)*

During the analysis of the focus group, it became clear that the points made around this topic were not fully covered by the existing coding. This led to creation of a new sub-category entitled *Engaging with mindfulness in severe illness: finding it difficult, finding it possible* (8.4a.1.1), to reflect the complexity of this aspect of experience. This related both to establishing and, to a lesser degree, to maintaining practice (7.4a.1 & 7.4a.2).

8.4a.2 Supporting people in 'making it my own'

As explored in the previous chapter, participants reported a diversity of ways of practising mindfulness (7.4a.3). I was interested to explore how the trainers viewed this diversity, particularly whether they considered any approaches 'better' than others in how they affected people's experience. Throughout the discussion, the dominant theme was of supporting participants to make their own choices about what worked for them. The trainers recognised that different approaches suited different people, and that their priority was to make mindfulness and meditation as accessible as possible to participants. They confirmed the approach of providing a 'toolkit' for participants (7.3.1), enabling people to select *"what works for them" (Valeri*e) and recognised that this would vary between individuals and over time. This led me to create a new sub-category, the title of this section, to reflect this flexible, supportive approach (8.4a.3.1). In response to specific questions, a number of particular points were considered, as will now be briefly explored.

The group considered whether it was important to take on the ideas and concepts as well as the practices of mindfulness. They noted that for some people the ideas, or even particular phrases, could be very powerful and bring about significant changes in their understanding of their experience. They also recognised that others did not engage with this more conceptual level, particularly at the outset, but focused on practical elements of the 'toolkit' and still benefited significantly. Echoing experiences described in the previous chapter, there was an understanding that people often took time to engage with different aspects of the course (7.4a.3.3.), and on some occasions the process of integration and change was a slow one rather than a dramatic transformation (7.5.3.2).

The varied use of the meditation CDs led me to explore whether the trainers considered an externally guided meditation offered a different depth or quality of experience to a self-

generated process. As mentioned above, the predominant response was *"I just want people to meditate" (Valerie)*, and to use whatever means they found helpful. The value of the CDs in providing a structure was noted, as was their role in reconnecting people to the experience and community of Breathworks and its values (7.3.3). Ursula reflected that encouraging the CDs' use from the outset was an important way of developing the key qualities of kindness and non-judgment, and could be problematic to introduce to people who preferred to continue with a previously established meditation practice. The trainers did not express any expectations that people would 'graduate' from using the CDs but rather emphasised the importance of using all possible strategies to develop and support a mindful approach to illness.

Reflecting on the place of regular meditation practice, there was a recognition that not everyone would maintain this, and that many were likely to operate a 'boom-bust' pattern which would relate to their state of health: *"you sort of boom and you think you don't need mindfulness and then when you have busted you do" (Stephan)*. Pain was seen as an important motivator, and likely to bring people back to practising (7.4a.3.1). This prompts a question, which it has not been possible to explore within this research, about whether people living with an intermittent condition may find it more difficult to sustain regular practice, even though doing so may reduce the recurrence of their illness. This certainly corresponds with Maya's experience, who had an underlying level of anxiety but experienced intermittent problems with panic attacks, and acknowledged: *"when you feel well you think 'Oh, I feel fine, I won't bother'" (Maya1)*. This may also relate to issues of identity and whether an intermittent condition has potentially less impact on how someone views themselves and whether they consider themselves to be living with a LTC.

Overall, the group acknowledged the difficulties – including their own - of maintaining practice (7.4a.2.4), and the importance of regular support (7.4a.2.5). They also recognised that for some, the Buddhist setting of many follow-up events could act as an obstacle (7.4a.1.3), with one trainer having addressed this by creating a space in her own house to which people could come for meditation sessions.

A final point explored with the trainers in relation to 'making it my own' was some participants' observations of the value of meditation as a valuable distraction from pain and distress, which appeared to contradict the emphasis on being in the present moment (7.2.3.3). Whilst clarifying that they *"wouldn't pitch the meditations as a distraction" (Claire)* when teaching, the group recognised that distraction was sometimes a necessary strategy for dealing with suffering, and that a variety of tools could be used to this end, particularly the guided meditations on the CDs. However, they emphasised the importance of awareness in this process, noting that distraction could be used mindfully if people were conscious of the decision they were making, but could become problematic if it was an automatic response to pain and difficulty:

…we all do it to block out a certain pain, it's what every human being does, we distract ourself by something pleasant and we are not thinking of all the difficulties we have got in our life at the moment, but if you were to try and live in your life constantly distracting yourself from it then it would just be causing more pain. (Stephan)

Mindfulness was seen as offering a way to bring a greater level of awareness, which enabled choices to be made about whether to choose distraction at any given time, but also to make more informed, positive choices about the <u>kind</u> of activity to use as a distraction (7.3.5). Harriet recounted a recent example of getting "into a bit of a state" and then recognising her need for distraction and selecting to listen to some music:

…it felt like a choice to do something which I felt would introduce some pleasantness into my experience in a way that I was mindfully choosing to do that was going to be beneficial rather than adding to the problem. Yes, you could say it was a distraction but to me it was choice. (Harriet)

The trainers recognised the challenges of moving towards suffering, and emphasised the need for people to feel in control of how they worked with this approach:

I think it's really important people know that they can chose when to look at their pain, when to look at their suffering and have some idea that it's somehow good to look at it. […] it can be months and years before someone is ready to do that, but in the meantime if they are blocking it with blissful meditative states well you know that's just the process isn't it? (Ursula)

This demonstrates another aspect of *'Starting where I am'*: taking into account not just the difficulty being experienced, but the person's capacity at that time to deal with it. The role of kindness was again stressed in this context (7.4b.2.5), and a respect for people making their own choices about the strategies they used (7.4a.3.6).

8.4a.3 Adapting mindfulness practices and ideas to meet people's needs

…if you just taught mindfulness meditation to people what would be different, what would be missing, what would happen in terms of what is it that Breathworks adds to that core? (JL, Facilitator)

In response to the question above, the group explained how the core teachings of mindfulness were adapted to make mindfulness practically accessible and of most benefit for people with LTC. As this topic had not been explored previously, the analysis led to the creation of a new sub-category, the title of this section (8.4a.3.2). The trainers emphasised how Breathworks teaches *"a whole method of working with suffering" (Stephan)*, rather than just awareness, to enable people to work effectively with their illness. A number of key adaptations were identified, many of which had been highlighted by participants in the previous chapter as particularly important to them.

The active emphasis on 'seeking the pleasant' (7.2.2.1) was seen as a necessary counter-balance when *"you are <u>so</u> focused on your pain and difficulty, that's taking all your energy and your attentions" (Claire)*. They noted that non-judgemental awareness alone may not create a sufficient shift in perspective, particularly in instances where people have had a long period of low mood and may *"not notic[e] that you are seeing the world through dark glasses" (Ursula)*. An additional encouragement to see more positive aspects of experience, together with a focus on kindness as explored below, was therefore seen as key to ensuring that people 'started where they were' with a balanced view of their situation.

The group also described how mindfulness ideas and practices were tailored to the context of health and illness. For example primary and secondary suffering were described in relation to illness and reactions to it, and 'applied mindfulness' activities such as the diary and mindful movement were included to develop people's awareness of their habits and patterns, needs and limits, in both the immediate and longer term. Participants' accounts of having learnt to apply their previous knowledge of mindfulness and meditation to their illness (7.3.1) confirmed that this applied approach was valuable, even for those with experience. Reflecting the broad applicability of the ideas and practices, James observed how mindfulness had the effect of *"open[ing] you to be able to make other changes in your lifestyle that are not directly related [to illness]",* a point made by many participants.

8.4a.4 Considering the role of meditation within mindfulness practice

As discussed in 2.3.4, not all mindfulness training includes meditation as a key element, and I was therefore particularly interested to explore what role the trainers considered it to have in people's experiences, and whether they saw it as essential to the practice of mindfulness. This led to the addition of a further sub-category, the title of this section (8.4a.3.3), in 'Making it my own' (7.4a.3).

The group considered the purpose of teaching meditation in the Breathworks context, differentiating this from a Buddhist meditation course. This served to highlight the purpose of the course as a whole, which is to support people to be more aware of themselves and manage their illness better. The impact of this difference was clarified in relation to the use of the CDs:

…one of the things we are teaching people, it's not to get into a meditative state, it's actually to be aware of what's going on […] it's about mind training, whereas if you were trying to get into a deeper concentrated sort of state it [the CD] could get in the way of it. Since we are just training people to have these moments of awareness all the time then it would be pretty normal [to use it] (Stephan)

In this instance, there was recognition that an externally guided meditation may reduce the depth of meditation, and limit awareness of some aspects of experience; however, if it enabled people to maintain mindfulness practice and develop non-judgemental awareness of their difficulties, this was a more important goal in this context (7.4a.3.6).

Claire observed how a sustained period of observing her experience through meditation was essential to bringing an awareness of the changing nature of her condition:

…a big breakthrough for me with my own condition was discovering that this <u>massive</u> hard rock I had on my shoulders was not actually as massive as hard a rock as I thought, but actually my physical experience was more fluid, that it could change moment by moment… (Claire)

She contrasted this with her experience of everyday mindfulness, which did not provide enough 'distance' to notice these subtle but significant changes, awareness of which contributed to the shift in perspective discussed in 7.2.2.3. Although this was not mentioned, it seems likely that <u>regularity</u> of practice could also contribute to this insight,

enabling monitoring and awareness of changes that occasional practice could not offer. Others also emphasised the necessity of stopping sufficiently to notice their habits and patterns; this reflects Nadia's observation of the value of meditation in providing a greater sense of perspective than informal mindfulness (7.4a.3.2).   It seems therefore that the absence of formal meditation practice could limit a person's ability to step back and notice very familiar aspects of themselves and their experience (7.2.2.2), and gain less benefit as a result.   This echoes the observation above that practising mindfulness without actively seeking the pleasant may not enable people to see positive aspects of their experience due to a habitual negative outlook.   Meditation may therefore offer a way to gain greater awareness of and insights into deeper, less conscious, layers of experience, and so offer further potential for change than informal mindfulness alone.

The trainers expressed a range of views on the role and centrality of meditation, including suggesting that mindfulness might be maintained through very short stops or through breath awareness rather than formal meditation. Meditation, at least in this context, was thus a means to achieving particular ends, with a number of the group observing that the length of meditation practice needed was therefore to some extent determined by how long it took to reach that end:

…it's getting that peace within and if you only need, if you can do that sat on the toilet between arguing with your mum or, then that's all you need to do, it's using the breath and getting, I think once you start getting that peace you extend it longer and longer. (Josie)

This understanding was not specifically mentioned in the previous chapter, but seems to relate to the pattern of 'practising on demand' identified in 7.4a.3.1, where the frequency and type of practice was affected by the level of difficulty being experienced.   These approaches indicated a flexible attitude to the use of formal meditation, and reflected another aspect of *'starting where I am'*, responding to need rather than necessarily committing to a fixed frequency or length of practice.   This suggests that it may be possible to maintain a level of mindfulness with little or no formal meditation practice in some instances, but on other occasions, such as times of greater pain or stress, a considerable amount of practice may be needed. The motivation to continue formal practice could then, to at least some degree, depend on whether the level of benefit obtained from informal practice alone was perceived as sufficient by an individual. Certainly, as described previously, a change in people's experience was an important motivator for continued practice (7.4a.2.2), and this was confirmed by the trainers:

…I think once you have got that feeling and you know that it helps, you extend it, so it will end up in meditation… (Josie)

The ability to maintain a state of mindfulness without formal meditation may also relate to how much practice people have done in the past. This reflects some participants' accounts of how, after an initial and sometimes lengthy phase of regular meditation practice, their attitudes and behaviour remained transformed even though they no longer maintained this practice (7.4a.3.3). The trainers however largely concurred with the contrasting experience of finding it difficult or impossible to remain mindful in daily life without a supporting meditation practice (7.4a.3.1). As meditators and predominantly practising Buddhists, it was to be expected that the group would value and be committed to formal

mediation. They recognised however that this was not necessarily the most beneficial approach for everyone, and emphasised that integrating mindfulness into everyday life was of equal or greater importance than a period of meditation (7.4a.2.3, 7.4a.3.2). Identifying the value of focusing on process rather than outcome (7.4b.3), they also recognised the need to avoid a *"that's going to solve this" (Josie)* approach to meditation.

8.4b Finding my way with my illness

8.4b.1 Demonstrating mindfulness in action

As identified previously, course participants had highlighted how the trainers provided an important example of living well with illness using mindfulness by demonstrating greater awareness and responsiveness to needs. Although the trainers' own experiences were not a topic for discussion, their mindful way of living was vividly illustrated within the focus group in the way that they behaved, both towards themselves and each other. Reflections on this experience led to the creation of a new sub-category, the title of this section (8.4b.1.1), within the *'Finding my way with my illness'* sub-theme (7.4b). This reflected many aspects of this part of the analysis, as will now be discussed.

From the start of the session, a number of the group communicated clearly about how they needed to manage their own pain and energy levels, and then acted in a way which supported this during the session, as identified in the following field note:

> *Harriet spent the entire group lying on the floor, Claire moved on and off the floor regularly during the session, Valerie stood up and sat down at intervals. They asked to have a break and also only took the time agreed before coming back so were also respectful of my needs to make use of the time well. It's quite striking to think that the room had a number of people who were seriously ill and probably some of them in quite significant pain, which they were demonstrating by how they behaved and what they talked about, but this was not making it a heavy or depressing group to be in at all. These really are people who are living well with pain and illness. (Focus group reflections 10 July 2012)*

The ease with which the trainers communicated about their needs, and how readily this was accepted by the other group members, was no doubt partly a result of the well-established relationships that most participants had and their familiarity with the venue where we were meeting. It was also however a clear demonstration of 'mindfulness in action'. Participants provided illustrations of the 'timescales' of awareness and action identified in 7.4b.1, and in particular planning how to meet their needs (7.7b.1.2) and monitoring and responding in the moment (7.4b.1.1). Their self-care also provided a clear demonstration of aspects 'becoming kinder to myself' identified in 7.4b.2: they were looking after themselves and focusing on their own needs (7.4b.2.2), and explaining these needs to others (7.4b.2.3). Claire recalled her own transformation in discovering:

> *…I could be honest about how I was feeling and I could stand up, I could lie down like I am now, and nobody would make a fuss…*

This comment, and many others made throughout the interviews and focus groups, was important in highlighting that a transformation in people's behaviour <u>had</u> taken place and that these were not simply people who were naturally predisposed to such behaviour.

The other notable feature of the group's behaviour was their awareness not only of their own needs, but of others in the group. Participants were enthusiastic to contribute, and had considerable experience and ideas to share on the various topics; however, the conversation did not need a great deal of facilitating due to their awareness of each other. A similar consideration was evidenced toward me as facilitator. This was illustrated when I needed to change the batteries on a recording device during the session; despite actively participating in the lively conversation, Valerie noticed and immediately enquired whether I needed to stop. Such behaviour seemed to exemplify how mindfulness provides an awareness of all aspects of experience (7.2.2.2) and a connection with and kindness towards others as well as self (7.5.1.8). As indicated, this was identified to some extent in the previous chapter; however my reflection on the focus group led to it being further highlighted. This was done by amending a sub-category within 'Identifying benefits for others' to emphasise how greater awareness of others' needs contributed to improving relationships (7.5.2.2).

8.4b.2 Emphasising the importance of kindness

The importance of kindness in all its different aspects, *"whether it's in the modelling, the content and the practice of the kindly awareness" (Ursula)*, was repeatedly mentioned during the discussion. This reinforced the views expressed in 7.4b.2.5 and led to this sub-category title being amended to give it more emphasis. Kindness was seen as key in enabling people to *"soften towards themselves" (Ursula)* and move towards their experience, as well as encouraging them to actively move towards the pleasant and away from negative and self-critical attitudes (7.2.2.1). The practice of kindly awareness was highlighted for its role in reducing the isolation often associated with LTC (7.5.1.8). Its importance in developing compassion towards others was also emphasised, reinforcing the point made in the previous paragraph. The link between wellbeing and *"acts of generosity and thinking of others where you include yourself as well" (Stephan)* was also mentioned, particularly in the light of research findings touched on in 2.3.2.3.

8.5   Seeing a change

Although not specifically explored with the group, a number of trainers identified how practising mindfulness had *"turned my life around" (Claire)* (7.5.3.1). They also confirmed how their greater willingness to communicate about their needs had benefited others around them (7.5.2.1). Returning to the theme of kindness, they emphasized that self-care was not a selfish act, as is sometimes perceived, but was often helpful in that it made them more available to others (7.5.1.4):

> *…if I wasn't kind to myself and look after myself properly I wouldn't be doing any of these things, so to me being kind to yourself is the most unselfish act you are, because when you are in a good place you have got a lot more to offer. (Josie)*

A dimension of change identified during this discussion, which had not emerged previously, was the impact of the course on health professionals who had been trained by or referred patients to Breathworks. This led to the creation of an additional sub-category *'New resources and perspectives for health professionals'* (8.5.2.1) within the *'Identifying benefits for others'* category (7.5.2). Josie noted the reaction of psychologists working with hospice patients she was training, and their surprise at the difference that mindfulness made to a group of what they saw as *"immovable people"*. Two trainers commented that mental health professionals had seen a valuable role for Breathworks with people with psychosis. An additional benefit beyond the direct changes to the patients themselves may therefore be through the changes in the perceptions of professionals they relate to. By being aware of the potential of mindfulness to support improvements in wellbeing, even when the condition itself cannot be directly treated or cured, professionals are likely to be more willing to refer or recommend patients to mindfulness training or to explore the introduction of such interventions to their service.

8.6   Summary of chapter and developing the themes

The trainers' focus group provided confirmation and further insights into aspects of the process of engaging with mindfulness practice. As has been discussed, the discussion supported and refined the analysis developed and explored in the previous chapter. The challenges of mindfulness were acknowledged and additional perspectives were offered on factors affecting participants' 'readiness' to engage with the process. In particular the group reflected on whether certain types or levels of illness and suffering presented insurmountable barriers to practising mindfulness. To some extent, their views reflected experiences recounted in the previous chapter, confirming that high levels of mental distress, particularly anxiety, could prevent people readily engaging with the meditation practices. However, whilst recognising that extreme suffering could be difficult to 'move towards', they also recounted powerful instances where individuals in such situations had benefited from mindfulness practice. This highlights the challenges of establishing who will benefit from mindfulness, and suggests it relates more to the complexity of individuals' particular circumstances, both internal and external, than any diagnostic label.

The group recognised the diversity of ways of practising mindfulness identified in the previous chapter, and were supportive of the individual choices people made to *'make it my own'*. They also identified how the concepts and practices of mindfulness had been adapted to make them practically useful to people with LTCs. This included emphasising actively seeking the positive aspects of experience and self to counter the frequently overwhelming focus on their illness and perceived failings that many struggled with.   The importance of kindness in supporting people's practice was again emphasised, confirming its pivotal role within the mindfulness process.

Whilst recognising that some people maintained a changed perspective on their life without regular meditation practice, the group identified how meditation enabled a greater 'stepping back' from and gaining perspective on experience than may be possible with informal mindfulness alone. Although this group unsurprisingly placed a high value on regular practice, they also emphasised the importance of integrating mindfulness into

everyday life. The decision to undertake formal mindfulness meditation practice may therefore depend on the degree of benefit obtained without it, which may in turn relate to individuals' expectations or needs. Finally, the trainers identified a wider circle of benefit from mindfulness practice, noting how it provided health professionals with new options to offer and further insights into the potential changes that were possible in patients' lives through improved management, rather than treatment, of their condition.

This focus group also offered a powerful demonstration of mindfulness in action. During the meeting, a number of participants with LTC acted in ways which clearly showed their awareness of their needs, and their willingness to communicate and take action to meet those needs 'in the moment'. This enhanced awareness also extended to others' needs, highlighting mindfulness' role in increasing the quality of connection and relationships. The trainers thus vividly illustrated the process of *'starting where I am'*, in particular demonstrating an awareness of their condition which enabled them to respond appropriately. Their behaviour provided a demonstration of many aspects of the analysis, confirming the core process and the themes associated with it as key to understanding how practising mindfulness affects the way people live with LTCs. In Chapter 10, I discuss these findings within the context of the wider literature concerning chronic illness experiences, and I identify the particular insights and contribution that they offer. Firstly however, to contextualise the findings, I provide information and reflections on my own perspective and experiences in relation to the research topic and process.

Chapter 9
Reflexivity

The importance of providing transparency in the research process was discussed in Chapter 4, where it was identified as a key quality criterion. It has been met within this study in a number of ways. A detailed description of the methods and the rationale behind them has been provided in Chapter 5, whilst Chapter 6 gives information about the research participants, thus providing context for the findings. This chapter further fulfils the criterion of transparency by providing information about my own perspective and position in relation to the research topic. It demonstrates reflexivity by exploring how my beliefs and experiences affected my interaction with the research process, and gives an insight into how this interaction may have shaped the findings.

9.1   Researcher's position and experience

9.1.1   Mindfulness and Buddhism

I have experience of mindfulness meditation and mindfulness practice, of finding these beneficial, and also of seeing other people benefit from them. I have also found it difficult to work with and integrate mindfulness into life on a consistent basis, and have been practising mindfulness to varying degrees over at least ten years. My experiences during the PhD prompted me to engage more deeply in mindfulness practice, as explained below.

I have had considerable contact with mindfulness meditation within various Buddhist settings, including the Triratna Buddhist Community (TBC). I do not describe myself as a Buddhist but am familiar with and in sympathy with core Buddhist principles. I have learnt and practised various forms of Buddhist and Christian meditation, including the meditations taught in the Breathworks programme. I have attended classes and retreats in a variety of Buddhist and Christian settings, and currently attend a Quaker meeting and a Zen meditation group on a relatively regular basis.

Prior to starting the research I had undertaken training in Hakomi, an approach using mindfulness as a tool for self-development. Whilst assuming no religious belief, Hakomi draws on Buddhist principles and practices, including a focus on the present moment and compassion for self and others. This gave me further familiarity with the concepts of mindfulness, as well as considerable experience of engaging mindfully with my own and others' experience. I continue to do this through seeing a Hakomi-trained therapist.

Sharing an apparently common language and experience had both strengths and weaknesses in undertaking this research. It was a disadvantage in that I was more likely to make assumptions about what people meant by various terms and experiences, and consequently not question and explore further. It was an advantage because many of the concepts and experiences are subtle and complex, and it would be difficult to follow particular lines of exploration without some familiarity with this territory. The

interviewer's lack of knowledge and experience is in fact mentioned in one qualitative study as a limitation which prevented detailed exploration of participants' experiences of MBCT (Smith et al., 2007). Weighing up these considerations, I decided not to attend the Breathworks course as part of the research process, as I felt it would unhelpfully affect data collection, giving me too much 'insider knowledge'. I explained this to participants during the interviews when relevant, and this encouraged them to give a more detailed account of their experience. Towards the end of the research however, difficulties with my own health led me to revise this decision and attend the course (see 9.2.2).

Although I came to the research with a positive experience of mindfulness and meditation, I was aware not everyone found it beneficial, and was genuinely curious about negative or neutral experiences. I was also aware that my perspective made me tend to assume that a negative experience was a 'problem', which could be explained or rectified by some change in the person or the teaching, rather than being a valid outcome in its own right. It remained a constant challenge to be aware of and question this assumption during the research, particularly given most people's strongly positive experiences.

9.1.2   Health, illness and self-care

I am a qualified homeopath working in private practice, where many of my clients have LTCs. The homeopathic understanding of health and illness emphasises the body's capacity for self-healing and seeks to identify ways to stimulate that process. It also views physical, mental and emotional illness as fundamentally connected, with all symptoms being considered as an integrated whole during diagnosis and treatment. The idea that an intervention targeted primarily at a person's mental and emotional state could affect their physical health was thus very familiar from my professional perspective.

The homeopathic consultation uses an in-depth interview to explore the client's health problems and their perception of these problems, the latter being particularly important within the diagnostic process. I am therefore very familiar with exploring how an experience is perceived *by the individual* and trying to minimise imposing my own interpretation on the situation. This perspective - recognising the existence of multiple realities, the influence of the observer, and the impossibility of identifying objective 'truth' - is consistent with my interpretivist position identified in 4.3.

My experiences have given me a strong interest in the role of self-care in building and maintaining health and wellbeing. I recognise the importance of people feeling in control of their lives, and of working with them as partners in the management of their health.

9.1.3   Research experience and training

I began the PhD without formal academic research training, and it took some time to recognise the transferable skills I had gained from prior experiences; the language of research in particular often made this 'translation' difficult. I found that my homeopathic practice, together with counselling skills training, equipped me for in-depth interviewing of people in distress and difficulty, whilst teaching and training experience provided relevant skills for conducting focus groups. Much of my training has emphasised reflection as a learning tool, and these experiences were valuable in enabling me to use reflexivity to

process and learn from the 'research journey', and to use memo-writing effectively within the data collection and analysis process.

During data analysis, I also recognised striking parallels to the homeopathic consultation process. The consultation seeks not simply to identify a range of disparate facts but to explore how they fit together to create themes and patterns in people's experience. The aim is to move from the particular to the general, from the details to the 'essence' of the experience. This very closely mirrored the process of increasing abstraction, using a combination of rigour and intuition, that took place during the identification of themes in the data, this parallel being perhaps particularly strong in GT.

Another consequence of arriving in the world of research from 'outside' was that I did not have an obvious academic disciplinary heritage or alliance, with its attendant concepts and terminology. Much reference is made within GT to the researcher's own pre-existing 'sensitising concepts' (Charmaz, 2001), and this idea was something I found difficult to relate to, partly due to the language used. I was obviously not a 'blank slate', but nor did I belong to a relevant 'world' such as sociology, healthcare or anthropology, bringing instead the perspectives outlined above. This unfamiliarity with disciplinary-based sensitising concepts had advantages and disadvantages; I was unlikely to impose such concepts on the data too early in the process, but was less able to draw on these ideas at a later stage.

9.1.4   Living with a long-term condition

I began the PhD in relatively good health, having had past episodes of musculoskeletal problems which had affected my functioning to varying degrees. During the course of the research however, my circumstances changed substantially. In my first year, I developed increasingly severe dermatitis on both hands which was painful and exhausting and, due to its location, extremely disabling. This eventually led in my second year to major changes in my working patterns: moving to studying part-time; obtaining Disabled Students Allowance (DSA) to fund additional equipment and support; and deferring data collection until this support was in place. An extension to my studies was also agreed by the University in recognition of the working time lost during this period. These changes were essential to my continuing to work, but also had an impact on my sense of identity: suddenly I was a "disabled student", trying to find ways to live with an uncertain and potentially LTC. I had to engage with a range of different institutions and procedures; I ticked different boxes on forms; I felt part of a different world whilst still living in my previous one.

Over a period of months, the condition improved to a level where it was not impacting significantly on my work, although it did not completely resolve. I therefore continued on a part-time basis, but increased my hours and began the third year in improved health. I continued my data collection, completing the first round of interviews by Christmas of the third year. These changes were welcome but were also surprisingly challenging to accommodate: who was I now? I no longer felt like I 'belonged' to the world of people with LTC, but neither had I fully recovered. Making plans was difficult. How much better was I, and was the dermatitis going to come back? Did I still 'deserve' help and if so, how bad did I have to be for this to still be acceptable, both to me and to others? I continued to claim DSA, although with some ambivalence as I negotiated these questions.

Over the next few months however, I developed an increasingly severe 'frozen shoulder', which caused significant pain and immobility, the symptoms increasingly impacting on my ability to work, both physically and mentally. Towards the end of my third year, as I moved from data collection to analysis and writing up, it became clear I could not continue. My supervisors and I agreed I should suspend my studies for four months to allow the condition to improve. Although clearly appropriate, this was a difficult decision; it was hard to let go of the work and I was afraid the loss of momentum would mean the study would never be completed. The fact that my peers were submitting their PhDs and leaving at this time contributed to a sense of failure and loss. I also realised how strongly my sense of purpose and identity was linked to the work, and felt these losses alongside the relief at no longer struggling to keep going. I was aware of Breathworks' potential to help and, as I had completed data collection and preliminary analysis by this time, many of my initial reasons for not attending no longer applied and I therefore decided to participate.

During the suspension, both the condition and I improved significantly and I returned to continue my studies in much better health, although still on a part-time basis. My improved ability to work was a great relief and boost to my confidence, and also made it clear how much I had been affected by my conditions over the previous years. This was a helpful but painful realisation: it restored some sense of what I was capable of, but also revealed how much my struggles to work effectively had been due to my health and not my lack of ability, as I had sometimes believed.

Throughout this time, I gained clear insights into the subtle and complex effects of illness which would not otherwise have been available to me. These gave me an ability to relate to both the research participants and data in different and, I would suggest, deeper ways.

9.2 Reflections on my interaction with the research

9.2.1 A journey from researcher to user-researcher

I consider that in some ways, both the researcher and those researched are "subjects in their own studies."(Sandelowski, 1986, p30)

As described above, I found myself in a changing and increasingly close relationship to the subject of my research. I moved from an 'informed outsider' - having an interest in and some experience of mindfulness but broadly healthy - to a 'practising insider' - living with health problems that significantly affected my life. I therefore became very clearly a 'subject in my own study' although, as Sandelowski suggests, this role is always present to some degree. This affected my interaction with the research process in a number of ways.

Given my own prior experience and the accounts of the research participants, one of the strategies I explored to manage my experience was mindfulness. This included formal meditation and informal mindfulness of everyday experiences such as managing pain and discomfort, coping with the variability and uncertainty of prognosis with the dermatitis, and adjusting to depending on other people for many basic needs. Although I did not always sustain a daily meditation practice, I used mindfulness throughout the experience and found it on many occasions to be a helpful, though sometimes challenging tool.

I became aware that my engagement with the research data changed from observation and interest to include an aspect of 'user-testing', where I was exploring the relevance and resonance of ideas within my own life. This applied particularly to the interview and focus group data, where participants' insights and strategies regarding their use of mindfulness were often directly relevant to my experience. Finding these ideas and strategies valuable in my own life provided further 'triangulation' with participants' accounts, as well as increasing my gratitude and respect for these individuals. This was clearly a very particular and subjective perspective through which to be viewing information, but one I was very aware of, in contrast to others which may have remained at least partly unconscious. It was also directly relevant to the research topic and may have helped to deepen the insights which have been gained into it.

To a lesser degree, a similar 'user-testing' took place in my engagement with published material, where I assessed its value partly for its resonance and practical usefulness to my own experience. Conversely, I considered the relevance of personal mindfulness experiences and learning (e.g. through the Zen meditation group) to the PhD material, and integrated these insights and understandings where appropriate. There has therefore been a perhaps unusually large two-way exchange of information and experience between my research and the rest of my life, all of which has been channelled and filtered through my own perspectives. This has given me a clear sense of how the researcher becomes a medium through which the research takes place, rather than being external to it.

9.2.2   My experience of Breathworks

As noted in 9.1.4, I attended the Breathworks course to manage the challenges of my health problems and make best use of the suspension period. I considered the timing avoided over-influencing data analysis, and that my experience could also provide valuable additional insight.

The course was held at a local TBC centre and facilitated by two experienced trainers, one of whom I had met through their participation in the research. Before booking, I discussed my participation with this person to clarify the role in which I was attending and the potential impact of our previous contact. I attended as an 'ordinary', self-funding participant and received my own set of materials and CDs. During the introductions, I mentioned my research but emphasised that my reasons for attending were personal. I attended nearly all the sessions and engaged in the homework, including meditation practice. I occasionally shared information I had gained from the research, but participants' anonymity was maintained at all times. I found the course well taught, and beneficial in a number of ways, this also appeared to be other participants' experience. The following reflections on my experience are written with reference to the themes and categories identified in the previous chapters.

Despite being 'off sick' I found integrating regular daily meditation practice extremely difficult, and this did not become easier as the course went on. Other members of the group also struggled to varying degrees, although everyone undertook some home practice within their varyingly demanding lives. This experience gave me a powerful insight into the commitment and effort involved in changing habits and patterns of life (7.4a.2.4). It also reinforced my sense that the research participants represented a

distinctive group of people who had managed to make that commitment and effort, often starting with very regular home practice during the course (7.4a.2.1). If my experience and that of others on my course is typical, this group may be a minority, although part of a continuum in which most people practise to varying degrees. It would be interesting to explore whether there is a link between this early commitment and ongoing practice.

I was aware that compared to other people in my group and the research participants, my health problem was more recent, less severe and of a reasonably predictable, time-limited nature. Some aspects of my experience were therefore different. While this did not affect the relevance of the course, it meant some of the motivations for fully engaging with the process may have been missing e.g. feeling desperate or having tried many other unsuccessful approaches to my problem. This may have contributed to the degree to which I engaged in the home practice, highlighting again the complexity of factors affecting an individual's 'readiness' to benefit and their motivation for ongoing practice (7.4a.1.1).

Whilst reporting difficulties with integrating mindfulness practices, it was also apparent many of us were exploring ways to modify practices and ideas to suit our situation: doing shorter meditations; selecting relevant parts of what was taught; or remembering a particular idea in a difficult situation (7.4a.3.6). The trainers were supportive of this process (8.4a.3.1), which was helpful in allowing me to selectively identify a few key changes rather than becoming overwhelmed by the range of potential strategies and practices.

Even though I did not always manage daily formal home practice, I gained significant insights into my experience which led to various changes in my behaviour and perspective. This was also evident for other people on the course, our experiences echoing those of the research participants. I found it impossible to entirely leave aside my 'researcher hat', and often found myself slotting people's comments into categories and themes from the analysis. It was interesting to note the close 'fit' between these experiences, which provided further informal confirmation of the developing coding structure. This observing perspective did affect my ability to fully engage in the course experience to some degree. This was not a surprise, as I was already aware of this happening in relation to other mindfulness-related experiences in life. The benefits I gained however were still extremely valuable (7.5.1).

The meditations provided a direct experience of key principles such as acceptance, choosing the focus of attention, and broadening awareness to encompass all aspects of experience. I found being led through the meditations in the group was a helpful way to begin engaging with these sometimes challenging ideas in a safe environment. This made it more possible to continue practising at home. Applying mindfulness to daily life also proved helpful, particularly completion of the diary of activities, which revealed unhelpful patterns of behaviour (7.4b.1.6). This led to me making practical changes, particularly building in 'pauses' between activities to step back and assess how I was, and to shift briefly from 'doing' to 'being' mode (7.4b.1.1&2). The meditations often provided a helpful structure for these pauses, and enabled me to then continue with activities in a calmer, more effective way. I still regularly use the 'three minute breathing space' for this purpose (7.3.1).

Like many people, I was struck by the trainers' ways of relating to us, which powerfully demonstrated the core principles of acceptance, non-judgement and kindness. We were encouraged to allow ourselves to consider, ask for and receive what we needed. This behaviour was also modelled by the trainers towards themselves, one of whom was living with a LTC (7.3.4.1). This focus on kindness was important in enabling me to recognise some of the self-critical attitudes I held and that it was possible to think and behave differently. I learned to 'let myself off the hook' when I did not meet my sometimes unreasonably demanding expectations, a change I have maintained to at least some degree (7.4b.2.1).

9.2.3 Disclosure of my own experience

On commencing data collection, I reflected on what constituted an 'appropriate' relationship with participants and what level of personal disclosure to offer, particularly in the light of my own experiences. My feminist perspective identified in 4.3.2 also prompted a concern to avoid appearing to be 'an expert' in mindfulness and meditation, as I considered this could create an inaccurate and unhelpful sense of hierarchy. These questions remained as the research progressed, particularly during the second interviews when relationships had inevitably developed further.

The dermatitis was at its most severe prior to data collection; thus by the time I started interviewing, disclosure of my health condition had become a choice, it generally no longer being severe enough to visibly affect my functioning. I considered what impact disclosing my own experience would have on the interview process. Given the limited time available, I was concerned not to focus too much attention on my own experiences, and therefore decided not to routinely tell people. I was also aware of feeling my own condition 'wasn't that bad', echoing comments by a number of participants (see 7.2.1.2) who had struggled to fully acknowledge the impact of their illness on their lives.

Whilst not routinely sharing information, I made a decision to always answer direct questions addressed to me. I was struck by many participants' honesty and openness, and felt uncomfortable with walking into someone's life (and often their home), asking for important personal information, and then leaving without offering anything of myself in return. There were therefore occasions when I disclosed personal information, including about my health and experiences of mindfulness. There were also specific instances when I chose to do this pro-actively. On these occasions I judged that it helped to establish rapport, or felt someone had shared experiences or opinions which left them feeling uncomfortable because they did not know how I was reacting to what had been said. These decisions were based on a feminist understanding of the research relationship discussed in 4.3.2.1. I considered it was important on certain occasions to step outside the 'neutral researcher' role, to *"close the hierarchical gap between researcher[s] and respondent[s]"* (Ellis and Berger, 2001, p851), and engage more openly as another person struggling with similar issues and questions. This approach seemed helpful to participants without shifting the focus away from their own experience. It may also have contributed to reducing isolation the sharing of experience, as identified in the analysis (7.3.3).

9.2.4 Ensuring participant benefit

Feminist principles also led me to consider the extent to which the research process should be 'two-way', offering benefit to participants as well as the researcher. I was aware of the demands the interviews and focus groups made on people's time, energy or pain levels, and that I was asking them about potentially distressing experiences. I considered that I had a responsibility not only to avoid adding to the challenges people were dealing with, but to make the outcome as positive as possible for them. Section 7.4a.2.6 highlights many instances where graduates identified benefits from taking part in the research. The trainers also valued the opportunity for reconnection with each other and discussing a subject they were passionate about. This was epitomised in Valerie's comment of the focus group being *"just like a reunion".* These were welcome, although unintentional outcomes of the process; however, there were also instances where I consciously considered participant benefit.

During recruitment, I wanted to ensure people who had offered to participate in the research had a chance to do so. Whilst purposively sampling for interview, I was aware I was not able to offer everyone a chance to participate in this phase of the research, including some who had shared quite a lot of information even during the short screening conversations. I felt some responsibility to give these people an opportunity to contribute, and this added to my motivation for running the graduates' focus group whilst recognising the strong similarities in experience to the interview participants, as discussed in 5.6.1. This did not determine my decision, but was an influence on my thinking which it is important to acknowledge. Similarly there were a few occasions when there was some question of whether potential participants met the inclusion criteria, particularly in relation to ongoing mindfulness practice. In these instances I decided to include people, all of whom provided valuable information and appeared to appreciate participating.

For some participants, taking part in the research provided a valuable stimulus to their mindfulness practice. A number of people noted changes in their behaviour, particularly during the week of diary completion, which in some ways directly contradicted my intention that people continue 'as normal' during that time. I not only recognised this was impossible due to people's increased awareness of their behaviour (and perhaps a desire to 'look good' in the second interview), but also welcomed the increased benefit they identified gaining from this. I found it impossible to remain neutral or consider this a negative outcome, even if it did affect the findings to some degree.

Finally, during the interviews, where I considered it would offer potential benefit, I offered information about mindfulness resources and the findings of other research. In the second interviews and focus groups, I also shared general, anonymised information about areas of common experience with other participants. I am aware my decisions and actions have influenced the research, but from an interpretivist and feminist perspective I consider that *all* actions inevitably shape outcomes to some degree, and conscious choices can be made to intervene in ways that may improve those outcomes for participants. To provide transparency and thus ensure quality, however, it is important to make these choices explicit where possible, and this has been done in this chapter.

9.3 Conclusion

Based on Sandelowski's understanding of both researcher and participants being *"subjects in their own studies"*, the information in this chapter provides the final set of participant data for this research. It provides details of the perspectives and experiences I brought to the study, and how these affected my thinking and behaviour, particularly in relation to data collection and analysis. The accounts of the research participants explored in the previous chapters are filtered through my own particular 'lens', which will inevitably affect the findings to some degree. My critical realist perspective however leads me to consider that each person's interpretation – including my own – offers an insight into a reality which, whilst impossible to fully know, can be better understood through exploration of their similarities and differences. In order to fully explore the experience of practising mindfulness in relation to living with a LTC, the next chapter therefore considers the findings from this research in the light of other, wider understandings of chronic illness. This enables both resonances with existing knowledge and the new insights that this study offers to be explored, and their implications for future research and practice to be identified.

Chapter 10
Discussion and conclusions

10.1 Introduction and chapter overview

This thesis aimed to explore how practising mindfulness affected people's experiences of living with a long-term condition (LTC). It arose in the context of a recognition of the significant challenges presented by long term illness, both to the individuals and those who provide care for them, and a growing interest in and evidence for the role of mindfulness meditation-based interventions (MMBIs) in improving outcomes for people with a variety of conditions.

Two approaches were used to address the research aim: a comprehensive review of the MMBI literature and an in-depth qualitative study. The literature review (Chapter 3) identified positive outcomes, particularly for psychological measures, and a complex process of change in people's perceptions of their illness and themselves. It also revealed a lack of knowledge of longer-term changes, and of how mindfulness is integrated into and impacts on people's everyday lives. Using grounded theory (GT), the qualitative study explored these questions through interviews, diaries and focus groups with participants who had learnt and/or taught mindfulness through Breathworks' MMBI. Data analysis led to the identification of a core process and five interacting themes, each with a number of categories and sub-categories.

This chapter has two sections. Section 10.2 discusses the thesis findings, and explores their relationship to existing knowledge. It identifies how the research has contributed to understanding people's experience of mindfulness and, through exploration of its relevance to the concept of 'transition', how people learn to live with a LTC. Section 10.3 then reflects on the strengths and limitations of the research, including a consideration of how quality was ensured in the research process. It also identifies implications of the findings for knowledge, practice and future research.

10.2 Discussion of thesis findings

This section starts by identifying the findings from the literature review, both the overview of systematic reviews and the critical review of qualitative literature. It then explores the findings from the qualitative study carried out for this PhD, and discusses the relationship between these and the existing mindfulness literature, highlighting new insights as well as areas of congruence with previous findings. Aspects of the wider chronic illness literature are then considered, in particular the model of transition, in order to identify how the mindfulness experience relates to existing understandings of living with a LTC.

10.2.1 Findings from the literature review

As described in 3.1.1, a comprehensive literature review was carried out after data collection and analysis had been completed, following the approach recommended in GT to facilitate an inductively-driven process of theory development (see 5.6.4.2). An initial critical mapping of the evidence for MMBIs had however identified strongly positive outcomes for a range of psychological and quality of life outcome measures across many conditions and populations. It also revealed a wide variation in the quality of the research, and a lack of exploration of how practising mindfulness affected people's experiences over the longer term. The comprehensive review built on this mapping exercise, aiming to clearly establish what was already known about the effects and experience of learning and practising mindfulness, and how the thesis findings related to and informed this knowledge. The review had two elements: a Cochrane-based overview of systematic reviews, and a comprehensive review of relevant qualitative literature.

The overview included 26 systematic reviews of the effects of MMBIs across a range of conditions and interventions. Whilst these, and the trials they were based on, were of variable quality, five high quality reviews contributed to a substantially consistent picture. Improvements in depressive disorders, particularly recurrent depression, were strongly supported, although the evidence for other psychological conditions, such as anxiety, was limited by lack of data. In populations with physical conditions, significant improvements in psychological wellbeing, including anxiety, depression and distress, were clearly evidenced. These findings were broadly consistent across a wide range of conditions, with variations in one review (Lakhan and Schofield, 2013) potentially resulting from use of different outcome measures as much as any 'real' difference in people's experience.

Evidence for changes in physical health measures, such as pain and fatigue, was much less conclusive; no change was identified in the majority of included trials, although these measures had been investigated to a much more limited extent. These findings however were balanced by positive changes in measures of pain acceptance and coping, suggesting participants' experience of pain had significantly altered, even if its severity was had not.

The majority of data were based on comparison to treatment as usual or waiting list control groups. Findings were inconclusive when compared to active controls, preventing specific effects of MMBIs being identified. There were some indications that the effects of MMBIs may be more cumulative than other interventions, but the limited amount of longer-term follow-up data precluded definitive conclusions being drawn. There was also inconsistent evidence regarding the relationship of outcomes to levels of home practice.

Despite these limitations, the findings of the overview suggested that people with most LTCs could potentially benefit from MMBIs. Although limited, reported data regarding adverse events and negative outcomes suggests there is a low risk of harm. Based on the evidence, it seems that people who are struggling emotionally with living with their condition and/or who are suffering from depression are particularly likely to find MMBIs helpful. The nature of the changes in people's experiences is however complex and not yet fully understood, prompting a growing amount of qualitative research to be undertaken.

A meta-ethnography by Malpass et al (2012) reviewing 14 studies of patients' experience of MMBIs, provided the focus for exploration of the qualitative research. Twelve further studies, mostly published since 2012, were also examined. As with the systematic reviews, the studies were of variable quality and considered a range of conditions and interventions using various methodological approaches. Despite this variation, they showed a strongly consistent picture of experience, as will now be outlined.

The meta-ethnography presented a three-phase model of *"the mindfulness process"* (Malpass et al., 2012, p60) which identified a transformation in participants' relationship to their illness, and ultimately to themselves. Each phase contained a number of processes, which also sometimes formed outcomes, highlighting the difficulties of separating the two in the mindfulness experience. The first phase highlighted the importance and challenge of 'turning towards experience', together with letting go of outcomes and being open to change. Phase two was characterised by four processes: stepping back and dis-identifying from experience; facing difficulty with kindness; focusing on the present moment; and taking a wider perspective beyond the illness which encompassed the whole of experience. These processes enabled people to observe their experience rather than be identified with it. This continued into phase three, which was marked by greater self-awareness and self-regulation, enabling more choice and control in responding to difficulty and an increased sense of 'agency' or ability to take action. This awareness, combined with acceptance, kindness and new practical strategies, promoted improved self-care. The outcome of this complex process was identified as a fundamental change in perspective, marked by the development of an 'observing self'*,* which enabled people to relate differently to their illness and the whole of their experience. The MMBI group's role in supporting this transformation was highlighted, as were the challenges which could impede it.

Malpass et al (2012) offer brief observations on how their model relates to wider literature regarding mechanisms of mindfulness and, to a lesser degree, the experience of living with a LTC. With regard to the latter, they particularly consider theories exploring people's changing sense of identity in chronic illness, including Carel's (2009) work on 'behavioural plasticity'.

The model developed in the meta-ethnography was supported in my critical review of the additional qualitative studies. The different aspects of experience described in the three phases could be seen in their findings, including the early struggles and the progressive change in perspective supported by the various processes identified above. Exploration of these studies also enabled more detailed, condition-related aspects of experience to be identified. Participants identified gaining greater insight into their patterns of behaviour and thinking, and more awareness of changes in their symptoms, enabling them to take action to avoid deterioration of their condition. They were also more aware of the transience of difficult experiences, and able to dis-identify from unhelpful thoughts, which increased their capacity to tolerate distressing situations. The centrality to the mindfulness experience of acceptance and kindness towards oneself was confirmed. Acceptance and the support of the group were identified as key to reducing people's struggle, shame and guilt regarding their condition. This then allowed them to be more aware of and less judgemental of their needs, and to regain a positive sense of themselves, which gave them permission to self-care more effectively in a variety of ways.

A number of additional dimensions of experience not reported in the meta-ethnography were also identified. The impact of mindfulness and acceptance on relationships with others was frequently highlighted, with participants identifying greater confidence in their communication, more tolerance of others and a feeling of connection. These changes were particularly evident in studies where participants had experienced difficult interpersonal relationships, but extended more widely, addressing the isolation and low self-esteem often associated with chronic illness. Improvements in symptoms – rather than changes in perception - were also reported, including pain, sleep, and cognitive function. Reflecting the overview's findings, there were no reports of aggravation of symptoms; this is notable as it was considered a potential risk in some studies.

A final area not included within Malpass et al's model was the experience of engaging with the course and practising mindfulness. This was particularly explored in Langdon et al's study (2011). This identified a journey with mindfulness practice based on three cycles: practising; slipping out; and returning to practice. Each cycle contained elements which reinforced current behaviour and those which triggered a change. The model illustrated the tension between the desire to integrate mindfulness into life and the struggle to practise. It also emphasised the self-reinforcing nature of experience, e.g. practising more as a result of seeing benefits and thus seeing more benefit, or an equivalent 'negative' cycle. Other studies provided insights into people's different patterns and choices of practice, and how they adapted practices to their own needs, illustrating how mindfulness provided a flexible and relevant approach to a variety of conditions.

Most studies in the meta-ethnography and the additional papers only considered changes in people's experience in the first few months after course participation. The meant that the longer-term perspective, and insight into further changes in people's thinking and behaviour, was largely absent. Negative experiences were also generally not represented. It is therefore difficult to know how widely these studies' findings apply to all those who attend MMBIs, although some studies include data from all the participants in a course, suggesting a positive experience in the large majority of instances.

10.2.2 Exploring the qualitative study findings and their relationship to existing mindfulness literature

As explored in Chapter 5, data were collected and analysed using GT methodology. As a result of this, a metaphor of an unwanted journey to an unfamiliar place was identified to represent the experience of living with a LTC. Figure 10.1, reproduced from chapter 7, shows the theoretical model which was developed from the analysis to represent how practising mindfulness had affected participants' journeys with their condition or, in most cases, multiple conditions. A core process, '*Starting where I am',* was identified, which encapsulated how participants' acceptance of their situation, combined with awareness of all aspects of experience, enabled them to respond appropriately to the reality of their symptoms and condition, neither ignoring nor overestimating their impact. This process was supported by and expressed in three key themes: *Getting a new perspective*; *Feeling equipped to cope*; and *Doing life differently*. Two further supporting themes, *Finding it*

difficult and *Seeing a change,* identified ways that the process could be either negatively or positively impacted respectively. The interrelationships between these themes was complex and, as emphasised in Langdon et al (2011), aspects of experience often acted to reinforce each other. This model, and its relationship to the existing literature, will now be explored.

Figure 10.1 Model of the mindfulness experience from the qualitative analysis
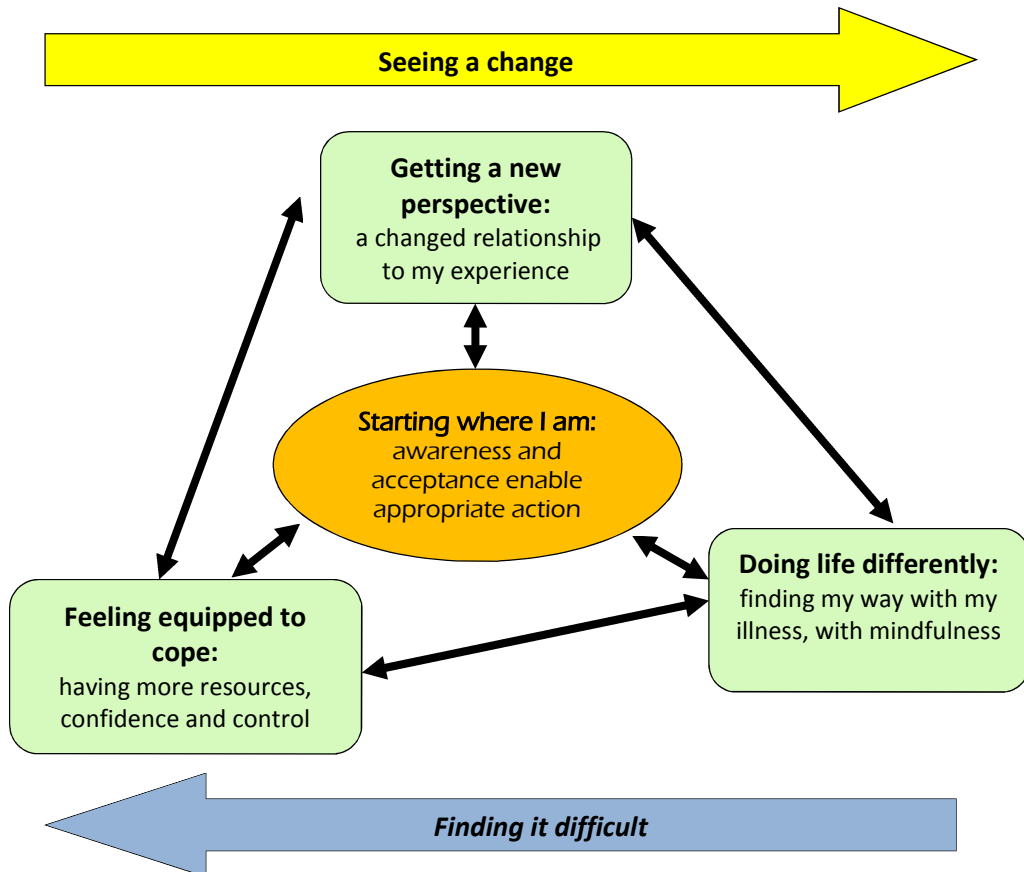
Unsurprisingly, many of the findings of the qualitative analysis strongly echo those identified in the literature review. The strongly positive experience of the majority of participants across many aspects of their lives reflects the broad conclusions of the overview, whilst the different aspects of the model in Figure 10.1 have strong resonances with the existing qualitative literature, including Malpass et al's (2012) meta-ethnography. The different aspects of the findings will now be explored through a review and discussion of the themes and core process, predominantly considering how they relate to the qualitative literature, but also noting the connections to the overview's conclusions.

In *Getting a new perspective: a changed relationship to my experience*, participants described how mindfulness brought about changes in how they viewed their situation, many of which were identified in the meta-ethnography and the additional papers. This included both facing up to the sometimes painful reality of their situation, and discovering new, wider aspects of the landscape in which they found themselves. The challenges and benefits of moving towards pain and difficulty formed a key aspect of *Finding it difficult*. This experience was more prominent in my study than in many others; it was only explicitly

mentioned in the meta-ethnography and two additional papers (Bermudez et al., 2013, Brown et al., 2010), and touched on in a few more. This prominence may have been a result of my specifically exploring the question of acceptance with participants, or its greater emphasis within Breathworks' training. Mindfulness's role in improving pain acceptance was also noted as a provisional finding from the overview. A dimension of this not present in other literature was some people's emphasis on balancing acceptance of their condition with continuing to hope for and make efforts to bring about improvement and change. Exploring this tension is a key feature of MBIs such as ACT and DBT interventions (see 2.3.4), and not particularly explored within MMBIs; the fact that it appears in this PhD study suggests it may be an underlying issue for many, even when it is not explicitly addressed.

A contrasting aspect of *Getting a new perspective* was using mindfulness to step back and see the bigger picture, both in a given situation and over time. In addition to appreciating the present moment, participants highlighted a new dimension of *actively* seeking pleasant aspects of their experience, a process specifically taught by Breathworks and not mentioned in other studies. This point was also discussed within the trainers' focus group, where it was linked to an emphasis on being kinder to oneself, which is explored further below. The subtle balance, also identified by Hawtin and Sullivan (2011), between mindfulness enabling attention control and providing a means of avoiding difficult experience was highlighted.

Participants' change of perspective was also evident in their letting go of focusing on the past or the future, and in particular 'stopping trains of thought': becoming clearer about what was <u>actually</u> happening rather than catastrophising about possible scenarios or ruminating about the past. This theme featured strongly in around half the qualitative studies e.g. (Brown et al., 2010, Chadwick et al., 2011, Dennick et al., 2013, Hoffman et al., 2012) and the meta-ethnography, and is at the core of mindfulness practice. Focusing on the present moment also enabled people to recognise the changing and complex nature of their experience and thus to be less identified with any specific aspect of it, particularly their illness. This formed part of a changed sense of identity, a theme touched on in many studies, and particularly present in a number using a phenomenological approach (Dennick et al., 2013, Proulx, 2008, Williams et al., 2011). This theme was present in my analysis, but less dominant, possibly due to the study's focus on how practising mindfulness affected daily living, and it not being a sensitising concept I brought to the research.

In *Feeling equipped to cope*, participants identified the resources which enabled them to *'start where they were'*, and the impact that these resources had had. There was a strong emphasis on the value of having practical tools and new concepts which helped people respond to and manage their symptoms and situation differently. Mindfulness had provided both a means to develop greater awareness, and strategies for responding to what they became aware of. Aspects of this theme not mentioned in other studies included gaining ideas and language which 'made sense' of and enabled people to talk about their experience, and 'having something to do' when feeling overwhelmed or lacking in motivation. Participants echoed other studies (Dennick et al., 2013, Hertenstein et al., 2012, Proulx, 2008) in valuing the group setting, which validated their experience, reduced isolation, and provided support which was often sustained after the course. The kindly

awareness meditation, a distinctive feature of Breathworks, also had an important role for some in building this sense of connection.

Learning and practising mindfulness had equipped participants to cope in a variety of ways which were clearly described by them. As a result of their experiences and of observing others, particularly the trainers, they felt more confident that they had tools and ways of thinking which enabled them to manage their condition more effectively, and to meet future challenges they might face. Having new self-care strategies also enhanced their sense of competence and autonomy in response to their condition, and in relation to healthcare professionals. Their accounts, in particular the increased sense of control and choice they had gained on their journey with their illness, reflected themes identified in the meta-ethnography and almost all other studies.   The ability to respond rather than react to situations was emphasised as a key benefit of practising mindfulness, and many instances of how this affected people's lives were recounted. This approach was also highlighted in the meta-ethnography and many of the additional papers in relation to mental, emotional and physical symptoms (Bermudez et al., 2013, Chadwick et al., 2011, Hawtin and Sullivan, 2011, Hertenstein et al., 2012)

Doing life differently explored how participants had learned to 'find their way', both with mindfulness practice and with living with their condition. In *Finding my way with mindfulness*, the struggles and commitment to establish and maintain practice, and the successes in integrating mindfulness into life were recounted. These reflected many of the themes identified in Langdon et al's GT journey with mindfulness practice (2011), and in other studies, including how seeing an improvement acted as an important motivation to continue. The PhD study however provided new and detailed insights into people's patterns and choice of mindfulness, at least partly informed by the diary on which the second interviews were based. It illustrated how people developed different patterns of practice, with some using mindfulness, particularly formal meditation, much more or only at times of need, such as when their illness was worse or they were experiencing other stresses. This approach was however balanced by others' emphasis on the necessity of regular practice for maintaining mindfulness and the benefits it brought. A similar differentiation between practising in response to need and practising regularly was noted in two additional papers (Cebolla and Barrachina, 2009, Williams et al., 2011). It seems that people tend to predominantly adopt one of these approaches, although my study indicated that some moved between the two, or aspired to more frequent practice.

This variation was one of many ways in which people reported learning to 'make it my own': to adapt their frequency and type of mindfulness practice to their needs and situation, including their condition. Whilst the process of adaptation is explored in some of the additional papers, particularly Chadwick et al (2011), my study reveals further sophistication and flexibility in people's use of mindfulness. This may well be a result of the longer timescale of practice that this PhD research has captured.   This flexibility included choosing on some occasions not to be mindful, or to focus on informal practice, to avoid being overwhelmed by pain or distress.   Kindness towards oneself was identified as having a key role in these choices, providing people with a guiding principle for how to respond to their experience, as is explored further below. It encouraged them not to push too hard in meditation - particularly in relation to becoming more aware of difficulty - and

to actively look for and appreciate what was pleasant in life. This balancing process reflected the tension between 'moving towards' and 'stepping back', and between acceptance and change identified above, and illustrated another way that participants *'Started where they were'* by being aware of and responding mindfully to their needs.

The experience of mindfulness becoming 'second nature' was distinctively described in my study, and may again reflect the length of time some people had been practising, and the strong commitment many showed to making it a part of their life. It was notable that significant changes in people's experience and way of managing their condition did not always appear to depend on consciously practising mindfulness. In some instances, participants no longer practised formal mindfulness meditation, observing that the changes in thinking and behaviour they experienced were now integrated into their lives. In contrast, others emphasised the value of regular formal practice; this unsurprisingly included the Breathworks' trainers. These different experiences may account for some of the complex and variable relationship between home practice and outcomes discussed in the overview and in Vettese et al's review (2009). Formal practice seemed to enable people to take more of a 'step back' from their situation; thus it may depend upon an individual's situation and level of need as to whether they consider this necessary. As many - including the trainers - observed, practising mindfulness is an effort and is likely to be discontinued if sufficient change can be sustained without it. This would accord with Langdon et al's (2011) findings of cycles of practice, but refines the understanding of 'slipping out of practice' to include a more positive aspect of internalising mindfulness and letting go of practice.

The second aspect of *Doing life differently* explored how participants learned to *Find my way with my illness,* with many elements mirroring those identified in relation to mindfulness practice. Participants noted how mindfulness had given them greater knowledge and understanding of themselves, which enabled them to *'start where they were'* by being aware of and responding appropriately to their health needs. The qualities of awareness and acceptance developed through mindfulness practice were seen as pivotal to enabling this to happen. They enabled people to make an accurate assessment of their situation and to be willing to make decisions based on this, rather than on how they might prefer things to be, or how they had been in the past. This process of awareness and response was seen to operate over three timescales: immediate response to need, day-to-day planning and long-term patterns of living. As is shown in Figure 10.2, in each timescale, depicted here as a cycle, awareness and acceptance facilitated appropriate action. These timescales inevitably overlapped to a degree, and although this point was not explicitly made by participants, this suggests that knowledge and insight gained on one timescale often informed patterns of behaviour on the others.

Figure 10.2 Model of cycles of awareness and action
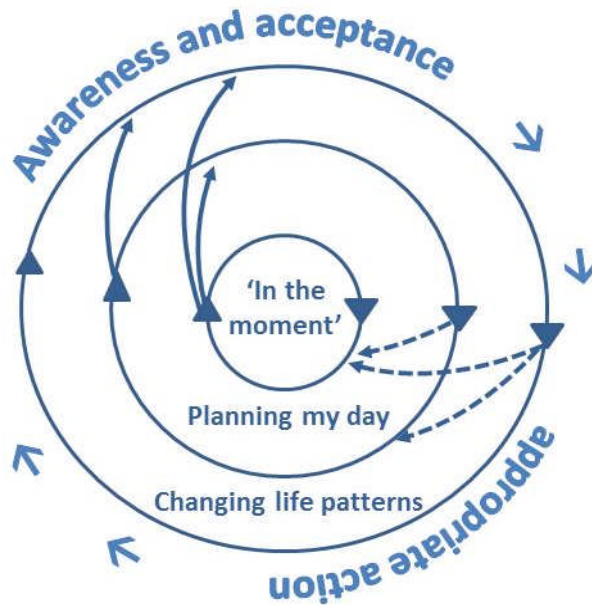
For some participants, there was also a prior stage to this process of '*Starting where I am'*, which involved accepting the reality of having a LTC at all. In these instances, mindfulness was key to starting people on the cycles of awareness and response discussed above. As illustrated in Figure 10.3, by taking the first step in becoming aware and accepting of having a LTC, people were then able to take further appropriate steps to address their needs more accurately. They could act in the various ways identified above which were likely to help them manage their condition and avoid further risks to their health.

Figure 10.3 Getting started on the cycle
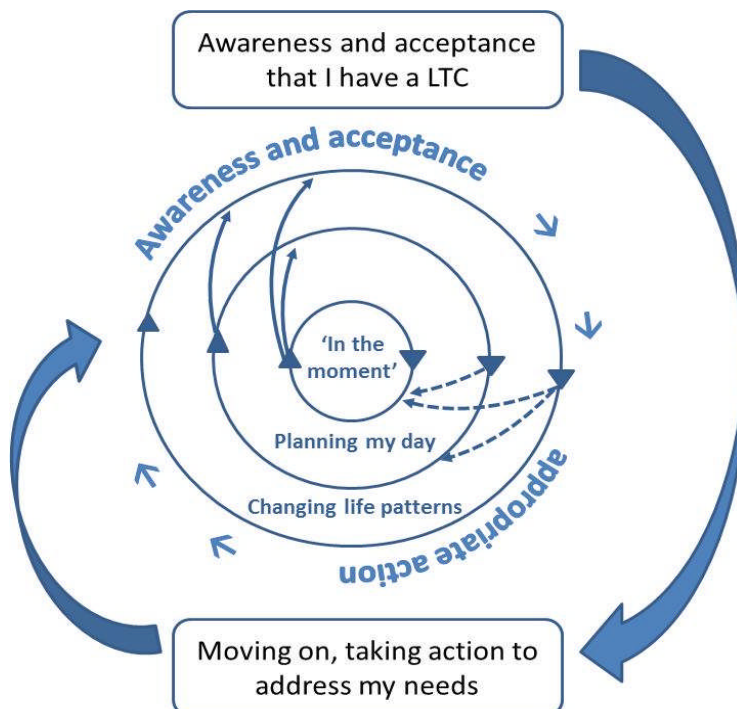
This theme of responding more appropriately and accurately to symptoms, including noticing warning signs, predicting the effects of activities, and changing patterns of life, is mentioned in both the meta-ethnography and some of the additional papers (Chadwick et al., 2011, Hawtin and Sullivan, 2011, Hoffman et al., 2012, Williams et al., 2011). It formed a much more central theme in my study findings however, and was fundamental to how the core process of '*Starting where I am'* affected how people lived with a LTC. A previous study of healthy participants highlighted how greater health awareness and self-care resulted from learning mindfulness meditation (Matchim et al., 2008), and my findings suggest very similar changes took place in a population living with chronic illness. Participants recounted numerous instances of being more *"tuned-in to how I am" (Tania)* and of acting differently as a result, with kindness to self again encouraging this change. In many cases this meant that they stopped sooner and did not push themselves so hard, being more aware of their limits and the consequences of ignoring them. This had the effect for some of reducing flare-ups and stabilising or even improving their symptoms.

Whilst reducing activity was the predominant direction of change, particularly for participants with conditions which were aggravated by overexertion, a contrasting pattern of choosing to push limits was also noted. Whilst the data are too limited to draw definitive conclusions, there was some suggestion of a condition-related dimension to experience. In particular, two participants with neurological conditions emphasised the importance of not over-limiting themselves through inaccurate perceptions of their capacity. More generally, many people described how mindfulness enabled them to push their limits in a more conscious way, often using the processes of prior planning and ongoing monitoring discussed in relation to Figure 10.2. This increased awareness was not always easy to maintain, and could be frustrating (aspects of *Finding it difficult*), but provided important benefits which then gave participants the motivation to continue.

Changes in behaviour were also supported by a theme touched on previously, that of people learning to be kinder to themselves. Kindness, considered by Malpass et al as *"both an outcome of the course and a component of the therapeutic process"* (Malpass et al., 2012, p70), is also frequently referred to in the additional papers (Bermudez et al., 2013, Hoffman et al., 2012, Proulx, 2008, Williams et al., 2011). The relationship between kindness and mindfulness is complex, but kindness - to self in particular - appeared to have a distinctive and significant role in the process of change. This theme may have been particularly prominent in my study due to it being explicitly emphasised within Breathworks. This led to it being explored in some detail with both interview and focus group participants, which gave valuable new insights into how kindness to self affected people's experiences of practising mindfulness in relation to their LTC.

Kindness was seen to offer people a new direction by which to navigate in making decisions; to ask, as one participant observed, "*What would make this easier?" (Louise1)*. As noted in the discussion regarding mindfulness practice, it also encouraged people to seek out positive aspects of their experience. Kindness was also closely woven with mindfulness in leading to changes in people's thinking and behaviour. Mindfulness supported the development of self-acceptance, which helped to counteract the low self-esteem frequently associated with chronic illness. Self-acceptance, combined with kindness, increased people's motivation to give their own needs greater priority. It also

enabled them to communicate more openly about their condition, and thus obtain the help that they needed. Whilst these changes were not always easy to make, especially for those who had previously ignored their condition, they had a significant impact on people's improved self-care, as is discussed further in 10.2.3.3.

A further new insight into participants' experiences, which was not reported in other qualitative literature, concerned a change from focusing on the <u>outcome</u> of particular activities to emphasising the value of the <u>process</u> of undertaking the activity: *"not getting [it] right … but yes, doing it right" (Clive2).* Whilst only mentioned by some participants, this change integrated and made sense of the apparently contradictory themes of 'letting go' and 'gaining control' which appeared frequently in people's accounts. Closely linked with *Getting a new perspective,* it illuminated how mindfulness gave people the awareness to recognise what was within their control, and the acceptance to let go of struggling with the things that were not. In the case of living with a LTC, often what had to be 'let go' was the <u>outcome</u> of a cure, or at least any fixed timescale in which improvement may take place. What participants 'gained control' of, however, was their response to their condition and the way they chose to live with it, i.e. the <u>process</u>. Mindfulness provided valuable tools to support both these activities, helping people to shift their focus with less difficulty or distress, and therefore change their experience.

Although less focused on particular outcomes, most people's experience of living with their condition was significantly affected, as was explored in *Seeing a change*. For many, these were transformational changes, for others there was more sense of a 'work in progress' or an experience of cumulative change, as provisionally identified in the overview. Many of the changes identified in my study reflect those highlighted in other research, both the systematic reviews and qualitative literature. Improvements in symptoms such as pain, energy and sleep were noted by some participants, and were also referred to in other qualitative studies (Bermudez et al., 2013, Brown et al., 2010, Cebolla and Barrachina, 2009, Hawtin and Sullivan, 2011). These improvements were often temporary, however, and not a feature of everyone's experience in my study; this corresponds with the more mixed findings of the overview in this respect. Findings in both my and other studies (Brown et al., 2010, Cebolla and Barrachina, 2009, Chadwick et al., 2011, Hawtin and Sullivan, 2011, Williams et al., 2011) confirmed the improvements in depression identified in the overview, and supported its tentative positive findings regarding anxiety.

In addition to these changes, participants noted greater coping capacity and ability to avoid illness-related problems. As a result of better management of their condition, they were often able to achieve and contribute more. These changes helped to improve confidence, self-esteem and optimism. The benefits of mindfulness were not confined to the experience of illness, however, and although the gains had come at the high price of living with a LTC, many participants identified improvements in their quality of life. They experienced calm and relaxation, and found more clarity and focus in their thinking. The improvements in relationships highlighted in the additional papers (Bermudez et al., 2013, Hoffman et al., 2012, Proulx, 2008) were confirmed in this study, with participants describing more kindness and acceptance towards others as well as themselves. This aspect of the findings was further uniquely developed in this study through participants' observations of how their own improvement had positively impacted on those around

them. A greater sense of connection with others and with life and their surroundings was also highlighted.

Notably however, one study participant's distress at trying to 'move towards' her difficulty prevented engagement with mindfulness practice, highlighting the challenges represented in *Finding it difficult.* A second participant did not recognise any changes in his experience as being mindfulness-related, suggesting the importance of the match between people's expectations and what mindfulness practice can offer. The question of 'readiness' and ability to benefit from mindfulness was particularly explored in the focus groups, and a complex range of factors was identified as impacting on this, both internal and external.

Consistent with the existing literature, my findings suggested changes in people's experience took place irrespective of condition. The similarities between the findings of my study of Breathworks and those of studies of MBSR and MBCT also confirm a strong common core of experiences across MMBIs, as identified in the overview. My findings also correspond closely with those in the meta-ethnography (Malpass et al., 2012), with some differences arising from the different focus of the research. The meta-ethnography predominantly depicts the initial transition taking place in people's experience as a result of engaging with mindfulness, whilst my study focuses on the ongoing experiences of practising mindfulness in everyday life over a longer period of time. In addition, whilst Malpass et al identify the overlap between process and outcome, and acknowledge the constant interaction between the different aspects of experience, this is not integral to their model, which depicts a linear progression. This complexity is better represented in my model of the mindfulness experience (Figure 10.1), which reduced the need to differentiate process from outcome.

The meta-ethnography identified the key role of mindfulness in transformation and change, a finding which was confirmed in my own research. As noted above, Malpass et al make some reference to wider literature regarding the chronic illness experience, but do not identify or consider existing work regarding 'transition' (Chick and Meleis, 1986, Meleis et al., 2000, Kralik, 2002), a concept which has clear overlap with their findings regarding transformation. This concept will now be explored in depth, as it appears to have strong resonance with themes identified both in my analysis and other studies, and offers new insights into the relationship between mindfulness and living with a LTC.

10.2.3 Relating the findings to existing chronic illness literature

As noted in 5.6.4.2, I purposely delayed exploration of existing literature regarding the chronic illness experience until the analysis was well developed, and I had formulated the metaphor of the 'unwanted journey'. At this stage, I became particularly interested in Meleis et al's (2000) work regarding 'transition', which recognised common elements in many experiences of change, including those of migrants and people who develop chronic illness. On further exploration, it became apparent that many of my findings resonated strongly with many aspects of the transition model. This model, rooted in a nursing perspective (Chick and Meleis, 1986), also had strong practical applications, which appealed to me and my concern to ensure the research was useful, as discussed in

10.3.2.4. A considerable amount of work has explored the relevance of the transition model to people with a variety of LTCs (Mengshoel, 2008, Baumgartner and David, 2009, Wilson et al., 2011, Halding and Heggdal, 2012, Adili et al., 2013). Having reviewed this literature in the light of my findings, it seemed that the experience of learning and practising mindfulness could be understood as a powerful facilitator of transition. It enabled many people to move on and *"live well with illness"* (Kralik et al., 2005, p15) and, as a result, to become skilled in self-care. The model of transition will now be outlined, following which its relationship to the study's findings is explored. Other work which adds relevant insights is also considered, particularly Paterson's 'shifting perspectives' model (2001b) and a recent meta-ethnography of experiences of chronic pain (Toye et al., 2013).

10.2.3.1 An overview of 'transition' in chronic illness

'Transition' is defined by Kralik et al as "a process of convoluted passage during which people redefine their sense of self and redevelop self-agency in response to disruptive life events" (2006, p321). Whilst the concept was originally used in anthropology in relation to the movement through key life stages, it has been developed within the nursing literature to explore how people relate to and come to terms with a range of types of change, particularly those in health and illness (Chick and Meleis, 1986, Meleis et al., 2000, Kralik, 2002). Transition is therefore distinct from change, although it may trigger or be triggered by it. It is the internal process of responding and adapting to change, affecting many dimensions of experience and often occurring over a long period of time. In the context of living with a LTC, it therefore encompasses far more than the direct changes brought about by illness. It recognises the complexity and depth of change which people experience, including to their sense of identity and way of being in the world. Meleis et al (Meleis et al., 2000) therefore suggest that a person has experienced transition when, to at least some degree, they have been able to reconstruct their life and identity and reach a place of balance and control.

Meleis et al (2000) identify a number of key properties of the transition experience. An individual's *awareness* and recognition of change appear to be important elements without which transition may not be possible. Awareness also directly affects *engagement*: involvement in the processes of responding to the change, for example by seeking information or modifying activity. As noted above, *change* is a key property of transition, whilst *difference* is also highlighted: feeling or being seen as different, or seeing others and the world differently. *Critical points or events* are a further key aspect, often triggering awareness and engagement, or marking a move to a new phase of the process. In its early formulations, transition was seen as having a *timespan* and as a linear movement through distinct phases (Chick and Meleis, 1986). More recent research has however suggested that in many instances this conception is inaccurate and unhelpful, and that the process is more lengthy, complex and multi-directional, and may be at least partially ongoing (Meleis et al., 2000, Kralik, 2002, Adili et al., 2013). This may be particularly true in chronic illness, where it is often not possible to reach a stable state due to the changing nature of the condition. Paterson's 'shifting perspective' model of chronic illness (Paterson, 2001b) provides helpful additional insights into this ongoing movement, as is discussed below.

The process of transition may be facilitated or inhibited by a range of factors, including the personal and cultural meanings attached to the experience and whether it is stigmatised or acceptable within society. Preparation, knowledge and the support of family, friends and healthcare professionals are important facilitators of transition, whilst marginalisation, poverty and inequality may inhibit access to resources to support it. Notably, the level of pathology has not been found to be a reliable guide to the ease of transition, illustrating the complexity of factors affecting this process (Chick and Meleis, 1986, Kralik, 2002).

Meleis et al (2000) identify a number of indicators that transition has taken place. *Feeling connected* with other people demonstrates that relationships, often disrupted during periods of change, have been rebuilt or recreated, providing a sense of security and meaning. This also enables greater *interaction* with others through which the meaning of the transition is clarified. The person feels *located* in the new situation and able to reflect on and interact with it, and develops new *confidence and coping* abilities. *Mastery* of skills and behaviours needed to manage change is seen, including accessing resources, making adjustments and taking action. Another key indicator is the emergence of a *new fluid identity* which integrates both old and new aspects of the self. This recognises that transition is fundamentally an *"inner reorientation and self-redefinition"* (Kralik et al., 2006, p323), the old self having been lost or disrupted by the experience of illness. Intrinsic to this process is an acknowledgement that an earlier reality has ended, which is essential to making sense of, and finding ways to adapt to, the new situation.

A number of studies have largely confirmed the value of transition as a way to understand the multidimensional impact of chronic illness, and the process through which people may go in adjusting to it. Kralik (2002) identified how illness precipitated people into a state of *"extraordinariness"*, where they experienced loss of control and self-esteem, a loss of their old selves, and alienation from others and from their body, together with feelings of insecurity, difference and fear. Many aspects of life which had been 'ordinary', i.e. taken for granted, were disrupted and became unpredictable. Over time, many – though not all - participants moved to a new *"ordinariness"* in which they found a place for their illness to fit in their lives. This took effort and active, conscious engagement; it also required a willingness to let go of the past and of previous expectations, and to live in and appreciate the present. It involved at least some degree of acceptance of their new situation. As Kralik observed, *"making choices to enable them to live well with their illness could only be achieved once women had the opportunity to resolve the poignancy of the illness experience"* (Kralik, 2002, p151). Through this process, people learned to recognise and appreciate who they were now, and thus to regain a sense of value and power in their lives (Kralik et al., 2005).

Transition also entailed a practical reconstruction of life with illness (Kralik, 2002). This was based on an ongoing process of learning about their body and its responses, identifying what changes were needed in thinking and behaviour, and developing new strategies (Kralik et al., 2004, Kralik et al., 2005). This enabled people to accommodate their illness and the limitations it imposed, such as by planning and pacing their activities. It also enabled them to push their boundaries, to access and take advantage of support, to give more priority to their own needs and let go of guilt at not meeting other's expectations (Kralik, 2002, Kralik et al., 2004). Awareness was essential to this *"conscious*

living" (Kralik et al., 2004, p263), which was an ongoing process, creating a sense of independence, control and progress (Kralik et al., 2005).

The support of others was confirmed as playing a key role in transition. It enabled people to tell their stories and, in some instances to hear those of others, providing a way for them to make sense of what had happened and, in the latter case, to normalise their experience. It facilitated the re-establishment of relationships and connections, and the reconstruction of identity (Koch and Kralik, 2001, Kralik et al., 2005). It also sometimes offered vital recognition for the progress people had made, and motivated them to continue with their changed way of life (Adili et al., 2013).

Highlighting the challenging nature of transition, Adili et al emphasised the length of time it often took people to move through this process and to change their perspective and behaviour (Adili et al., 2013). Its ongoing nature was also highlighted by others, who emphasise how 'readiness' to change is a continuing process rather than a threshold to be crossed, and one which evolves as people learn to come to terms with and adapt to their illness (Baker and Stern, 1993, Dalton and Gottlieb, 2003).

10.2.3.2   Mindfulness as a facilitator of transition

Reviewing my study's findings in the light of the transition model, it was clear that learning and practising mindfulness could be seen as helping to facilitate participants' transition in relation to living with their LTCs. Many of the characteristics and outcomes of transition were strongly present in the data, as will now be briefly explored.

Participants were at different stages in the transition process prior to attending the course, with some having already integrated their illness into their lives to varying degrees. Their decision to attend the course suggests that they already had some level of awareness, an essential property of transition, although for many this was balanced with struggle and resistance which prevented them engaging with their illness and its consequences. It is perhaps unlikely that someone who had not embarked on the transition process at all would attend the mindfulness training; certainly, this is one way to interpret the idea of 'readiness' which was discussed in the study. The course certainly however provided a 'critical point' in the transition process for many people, triggering a change in their response to their illness.

It was clear from the findings that mindfulness provided tools and support to enable participants to develop greater awareness of their illness; this was an essential prerequisite to them engaging with and managing it more effectively. Mindfulness also offered new perspectives and insights into experience which provided them with new ways of relating to their illness and themselves. This enabled important changes in people's identity to take place. Acceptance of their new reality and a shift towards a more fluid identity which integrated illness into their lives were highlighted in *Getting a new perspective*. The range of ways in which people had adjusted their behaviour through awareness, engagement and greater self-compassion were explored in *Doing life differently.* Participants had learned to *Start where I am,* recognising and responding to the needs and limits imposed by their illness, but making choices to balance these with other aspects of their life. The transition indicators of confidence, coping and mastery were particularly highlighted in

Feeling equipped to cope and *Seeing a change*. The importance of the group aspect of mindfulness training can be understood in the context of the transition model, where support is highlighted as having a key role in providing resources and conditions to facilitate the transition process. In addition, belonging to the group and - in this study - to the wider Breathworks 'graduates' community, helped many people to feel more connected, a key transition indicator. The course enabled people to find common ground with others living with LTC, whilst the Breathworks' explicit focus on kindly awareness helped to maintain and extend this sense of connection further, enhancing people's relationships with family and friends and, for some, providing a wider feeling of universality. Similar experiences relating to this point were also highlighted in existing literature, particularly in relation to improved close relationships, as has previously been explored in 3.3.4.2.

The greater acceptance and awareness resulting from mindfulness practice, together with an attitude of kindness towards self, also facilitated participants' communication and interaction with others about their illness and its impact. One aspect of this interaction was a greater confidence regarding disclosure of their condition, with less concern to conceal their illness and its effects. This was particularly evident in the trainers' behaviour, but also was referred to within other participants' accounts. Charmaz identified that disclosure is often linked to maintaining control and preserving a sense of self (Charmaz, 1995), with a concern to avoid others' judgements and to continue to appear 'normal' (Telford et al., 2006). A study of people with HIV/AIDS identified links between stages of transition and patterns of disclosure, with a movement towards a greater sense of choice and freedom (Baumgartner, 2007, Baumgartner and David, 2009). The greater ease in this respect described by participants' in my study thus suggested an element of transition had taken place as a result of mindfulness practice, particularly in relation to reconstructing their identity to incorporate their illness, and to *"redefine normalcy"* (Mengshoel, 2008, p1442).

The ongoing and challenging process of acceptance identified by study participants echoed similar experiences recounted in other work. Wilson et al (2011) suggested that acceptance may come and go over time depending on the context, whilst 'accepting non-acceptance' was identified as a way forward by a participant in another study (Kralik et al., 2005). As noted above, acceptance, coming to terms with a new reality, and letting go of the past and future form important aspects of the transition process. Probably because changes in these attitudes are explicitly emphasised within mindfulness training, experiences and reflections relating to them featured more strongly in my study than in many transition studies. Practising mindfulness appeared to provide distinctive, helpful resources to facilitate these particular changes, thus enabling transition to continue. Kindness towards self formed an important element of this process, encouraging people to value themselves and to feel less negatively towards their changed situation.

Participants' ways of managing their conditions, depicted in the cycles of awareness and action shown in Figure 10.2, reflected those associated with successful transition. People were able to accurately observe their condition and its impact, and then to respond appropriately based on their detailed knowledge and understanding of their needs. Through their skilled self-care, they demonstrated how they were located in, and had

mastery of their situation. The links between transition, mindfulness and self-care are discussed further in the next section. Participants' accounts also highlighted how mindfulness facilitated an ongoing process of adjustment to living with a LTC, confirming the understanding of transition as complex and non-linear experience. Further complexity was apparent in the ongoing dynamic balance identified between moving towards and stepping back from their illness. This movement reflects aspects of Paterson's 'Shifting perspectives model' of chronic illness (Paterson, 2001b), as will now be briefly considered.

Paterson's model identifies two perspectives which people may hold in relation to their LTC: *'illness in the foreground'* or *'wellness in the foreground'*. The former perspective is frequently associated with diagnosis or a significant change in symptoms, or with negative interactions with other people. Illness dominates the landscape and overwhelms other aspects of life and self, often leading to isolation from others. This focus also however preserves energy, which may be needed to cope with the shock of diagnosis and enable learning about the illness. In contrast, when wellness is in the foreground, *"the self, not the diseased body, becomes the source of identity"* (Paterson, 2001b, p23). People are able to take action to accommodate their illness, to feel in control and to appreciate and connect with a wider identity and life. Paterson (2003) emphasises that movement between the two perspectives is a natural part of the process of living with chronic illness, depending on a person's perception of their situation at any given time; a move towards 'illness in the foreground' is thus not to be interpreted as failure.

These two perspectives, and the movement between them, echo the balance identified by participants in my study between *'moving closer to difficulty'* and *'stepping back, seeing the bigger picture'*. They also appear to largely correspond to the states of 'extraordinariness' and 'ordinariness' described above (Kralik, 2002), and provide further insights into the complexity of transition. They highlight the multi-directional nature of the process, and how it may appear to 'go into reverse' in the face of new challenges. My findings shed further light on these patterns of movement. They suggest that transition not only took place over the longer term, in response to major changes, but also appeared to be part of everyday experience, as people became aware of and responded to their illness, whilst continuing to maintain a broader perspective on their experience. This complex interplay reflects and addresses the challenge identified by Paterson:

> *The major paradox of living in the wellness in the foreground perspective of chronic illness is that, although the sickness is distant, the management of the disease must be foremost; that is, the illness requires attention in order not to have to pay attention to it. (2001b, p24).*

Practising mindfulness therefore appeared to enable people to make the transition to living predominantly with *'wellness in the foreground'*, but not ignoring their illness or the changes it required, which could otherwise risk contributing to disease progression, or a denial of loss. The 'bigger container' participants identified provided a space for both awareness of illness and of the wider life and self of which it was a part.

10.2.3.3   Transition, self-care and the role of mindfulness

As discussed above, the findings from both the existing literature and my study indicated moving through transition enabled people to develop a sophisticated understanding and practice of self-care.   Through accepting and taking responsibility for their changed situation, people created a new identity which accommodated and was informed by their illness, but was not overwhelmed or defined by it. Their greater awareness and understanding of their illness provided confidence and clarity regarding what action was needed.   They regained a sense of value, control and choice, together with greater knowledge of how to manage their condition in order to live well with it.   This ongoing self-monitoring and self-care process was directed by their own detailed knowledge of their condition and needs rather than being based on external structures or guidelines.

Koch et al explored different strategies of self-management and proposed three possible models, with varying degrees of recognition and authority being given to the medical perspective of illness and/or to people's own experience (Koch et al., 2004). The approach described by participants who had made a successful transition, both in my and other studies, appears to closely resemble the 'Self-Agency Model' of self-management. This is characterised by people's broad understanding of the impact of illness on their lives, and by strategies centred on the individual's own knowledge and expertise in their condition (Koch et al., 2004). Whilst willing to engage with healthcare professionals, many were also experts in their own condition and confident in knowing what was and was not right for them. This sometimes led to them being considered 'non-compliant' (Kralik, 2002).

Exploring Koch et al's (2004) model in the light of the discussion above, it would seem that practising mindfulness, through its facilitation of transition, enabled people to gain more self-agency in their management of their condition and wider self-care.   This finding echoes Watson's exploration of MBSR experiences, which identified *'mobilising personal agency'* as its core category, and noted many similar changes in attitudes and behaviour to those discussed here (Watson, 2009).   My study has shown how the awareness gained through mindfulness provided participants with accurate and detailed information about their condition, and confidence as to how it could best be managed.   It has further distinctively identified how the emphasis on kindness towards self in Breathworks' training had a key role in supporting self-care, as through accepting and valuing themselves more, people were given permission and motivation to look after themselves and communicate their needs to others.

The implications for clinical practice of people's movement towards greater self-agency in their self-management strategies are discussed further in 10.3.3.1, whilst the distinctive role of kindness is further explored in 10.2.4.

10.2.3.4   Relating the findings to other recent research

Whilst it was not possible to consider the chronic illness literature in its entirety, a recently published meta-ethnography of patients' experiences of chronic non-malignant musculoskeletal (MSK) pain (Toye et al., 2013) highlighted a number of findings which resonated strongly with those in this PhD study. This substantial work, drawing on 77 qualitative studies, was therefore considered further. Toye et al highlighted a particular

struggle for recognition and validation of experience and self, which arose from the nature of the conditions patients lived with. A lack of explanation and diagnosis undermined people's sense of having a legitimate illness. This was often confirmed by others' attitudes, including healthcare professionals, who did not recognise the impact of the pain on their lives. As a result, people tried to hide their illness in order to appear like their old self, and felt alienated from both their bodies and other people. Whilst some aspects of this experience were condition-specific, many elements connect strongly with Kralik's "extraordinary" phase of struggling to come to terms with chronic illness, where identity is disrupted and there is a sense of loss of the past and fear of the future (Kralik, 2002). Such experiences were also described by many of my study participants as characterising their lives before learning mindfulness.

The meta-ethnography also identified how some people found ways of *"moving forward alongside my pain"* (Toye et al., 2013, p831). These again bear strong resemblance to the experiences of transition reported in the literature and in my study. These included acceptance of pain as an ongoing reality, and of the changes this meant for their lives, focusing less on what had been lost and learning to create a new self and enjoy a different life. Awareness again had a key role, through which people learned to listen to and understand their body and to live as fully as possible within its limitations. As a result they became confident in making their own choices about managing their pain, rather than relying on healthcare professionals' opinions.   Connections with others were also important in enabling moving forward, both from the support and validation of others with similar conditions, and in communicating their needs and limits to those around them. Echoing the PhD's findings, Toye et al note that people found these changes difficult to make, but essential in enabling them to come to terms with their situation.

The central role of acceptance and awareness in enabling people to live well with illness appears to be a strong theme in all these findings, together with support and validation from others. This suggests that although some aspects of experience may differ, and may add to or reduce the challenges involved, there are key elements which remain essential to the process of transition. Learning and practising mindfulness, particularly with an emphasis on kindness and connection, appears to provide one means of accessing these elements, which is effective for people across a range of conditions.

10.2.4 What this study adds

In addition to confirming many existing findings in the mindfulness literature, this PhD study provides important new insights into how practising mindfulness can affect the experiences of people living with LTCs. This section identifies eight key findings.

Firstly, for many participants, integrating mindfulness into their lives had brought about a profound change in their relationship to their condition, which impacted on both their thinking and behaviour. Analysis of these experiences led to identification of a model, based on a core process of *'Starting where I am'*. This highlighted how awareness and acceptance of their condition, developed through practising mindfulness, enabled people to take appropriate action to meet their needs. Further insights into how this process of awareness, acceptance and response operated were provided through identification of

three 'timescales', and the interaction between them. This served to highlight both the complexity and ongoing nature of the core process, which enabled people to continue to adapt to changes in their situation in both the short and long term.

Secondly, exploration of the findings in relation to the wider chronic illness literature has identified strong correspondences with the process of 'transition', through which people come to terms with challenging life changes. The qualities and skills developed through mindfulness, including acceptance, awareness and engagement with experience, confidence and coping, are key aspects of transition. This suggests that mindfulness can be understood as an effective facilitator of transition for many people. This is a new insight, which provides both an alternative perspective on the mechanisms of mindfulness, and more clearly locates the role of mindfulness within existing understandings of living with chronic illness.

Thirdly, potential links between mindfulness, transition and self-care have been identified. Associations between transition and greater self-agency in self-care have been highlighted in existing literature, and Matchim et al's (2008) mindfulness study showed improved self-care amongst healthy participants. The findings from my study build on and extend this work to people with LTC, suggesting that it may be through facilitating transition that practising mindfulness improves people's self-care. In particular, transition is related to a more self-directed model of self-care; this was evident in the findings, where participants expressed greater knowledge and confidence in relation to the management of their condition.   This further supports the suggestion of a link between mindfulness and transition, and offers insights into how practising mindfulness may enable people to come to terms with the challenges of living with a LTC and become skilled in their self-care.

Fourthly, the study findings refine understanding of the complexity of the transition process. They confirm existing recognition that change is ongoing, and may be two-way or fluctuating rather than linear, and further suggest that different trajectories may apply to different aspects of life. Identification of the 'timescales' of awareness and response particularly highlighted how people may adjust some patterns of living more than others; for example, changing their planning of activities but being less responsive to their needs in the immediate moment.

Understanding of the complexity of transition was further refined by exploring participants' experiences in relation to the 'shifting perspectives' model of chronic illness. The findings gave detailed insights into how practising mindfulness enabled people to negotiate the complex balance of demands in their lives. They learned to 'tune-in' to their illness without being overwhelmed by it, and to accommodate it within their broader experience and sense of themselves. This balancing process had clear resonances with the 'shifting perspectives' model, suggesting that mindfulness enabled people to live primarily with 'wellness in the foreground', whilst continuing to be aware of and take account of their illness. The complexity of people's experience clarifies and emphasises how patterns and processes of transition will vary between and within individuals, depending on their circumstances at any given time.

Fifthly, the diverse ways in which people integrated mindfulness into their lives and refined their patterns of practice offered new insights into how different aspects of mindfulness

practice can meet different needs. In particular, some participants' observations of continuing to benefit even after discontinuing formal practice sheds light on the complex relationship between home practice and outcomes. Levels and patterns of practice would seem to relate to individuals' differing expectations and perceived benefits from different mindfulness practices, as well as varying with the symptoms or stress being experienced at any time. These variations may well also relate to the degree to which people have moved through the process of transition.

Sixthly, this study provides new and clearer insights into the vital contribution to people's behaviour change of developing kindness and compassion towards themselves and others, an aspect of mindfulness particularly emphasised within Breathworks. Being more kind to themselves was a significant change of attitude for many people, and had a powerful effect on their thinking and behaviour. It gave permission and encouragement to value and care for themselves, and to meet the needs they had become aware of. This included feeling more able to communicate with others about their condition and needs without guilt or shame. Self-compassion also helped participants not to push themselves too hard, including on occasion allowing them to consciously choose not to be mindful of difficulty, but to take a step back from it. This linked to another distinctive feature of the findings, of learning to actively seek pleasant aspects of experience, which helped participants avoid becoming overwhelmed by their illness.

The findings suggest that, for some people, an emphasis on kindness and self-compassion may be essential to enabling them to engage with or sustain the challenges of mindfulness practice whilst living with a LTC. Furthermore, as noted previously, existing research suggests that self-compassion has a key role in mediating the outcomes of MBSR (Keng et al., 2012) and MBCT (Kuyken et al., 2010), whilst compassion/loving-kindness meditation interventions show some promising outcomes (Hofmann et al., 2011); a very recent meta-analysis confirms these findings (Galante et al., 2014). Other research has also highlighted the role of self-compassion in mental health (MacBeth and Gumley, 2012) and adjustment to chronic pain (Wren et al., 2012). Increased compassion for others has also been identified as playing a significant role in improving people's relationships (Bihari and Mullan, 2014). Thus, increased kindness developed through mindfulness is likely to contribute to a range of improved outcomes which, as noted earlier in *Seeing a change*, provide increased motivation to continue practice. These findings in relation to kindness, change and self-care also suggest that kindness may form an important facilitator of the transition process which has not been fully recognised or explored in existing work.

A seventh new understanding of the mindfulness process identified in this study was how participants benefited from a shift towards focusing on the *process* of their actions, rather than the *outcomes* of them. This shift in perspective had a key role for some in increasing their sense of control, and was facilitated by focusing on the present moment. Participants were more able to let go of the outcomes of their actions, which were outside their control; in this context this particularly referred to striving to improve or resolve their health problems. They learned instead to put their attention and energy into what was in their control, which was the process of living with the condition in the best way possible.

Finally, the literature regarding transition and the shifting perspectives model explore

people's experiences of chronic physical illness, but do not consider how these processes may relate to mental illness. The findings from my study, where some participants were living primarily with mental health problems, suggest that the changes arising from practising mindfulness largely transcend categories of illness. People with varied and multiple conditions described a new relationship to their illness and themselves characterised by greater acceptance, awareness and self-care. The findings thus suggest that the models of living with a LTC considered here may be applicable to a wider population. They also appear to resonate with the concept of 'recovery' proposed in the field of mental health, which suggests that people can come to live well with mental illness, and find a new sense of value, meaning and purpose (Anthony, 1993). Whilst this concept has not been explored in any depth here, it appears to lend weight to the view that whilst some aspects of experience may differ, living with any LTC has many similar dimensions which can be positively impacted by mindfulness.

10.3 Reflections and implications

In this section I consider two main areas:

1. the strengths and limitations of the study, including how quality was ensured throughout the process;
2. the implications of the research in the wider context, both its clinical applications and future research directions.

10.3.1 Strengths and limitations of the work

This PhD has provided a thorough and up to date review of existing MMBI research findings. The overview of systematic reviews in particular offered an innovative approach, giving clear insights into the current RCT evidence for MMBIs and its limitations. An overview has not previously been carried out in in this field, and the process revealed significant duplication of systematic review findings. The strengths and limitations of the overview are discussed separately in 3.2.4. In addition, through a critical review of a meta-ethnography of mindfulness experiences, and its integration with more recent qualitative work, the literature review provided a detailed insight into current knowledge and understandings of people with LTC's experiences of MMBIs.

The empirical qualitative research, which formed the main body of this thesis, had a number of strengths. It was based on Breathworks, a MMBI which has only been researched to a very limited extent. This study thus helped to identify the common and differing aspects of participants' experience across this group of interventions. It showed that 'the Breathworks experience' very closely resembled that of MBSR and MBCT participants, but revealed a greater emphasis on kindness and compassion and how this affected people's thinking and behaviour, reflecting the more central place this theme has within Breathworks.

The diversity of conditions represented within the sample formed another strength, which the GT process of theoretical sampling enabled to be explored in considerable depth. A coherent picture of the experience of practising mindfulness emerged, which to a very

large extent appeared to be independent of the specific LTC, with variations reflecting different applications of mindfulness to specific symptoms. The degree of benefit obtained did not appear to relate to the type of condition, or even its severity in some instances, but rather to other factors relating to the individual and their 'readiness' to benefit.

One poorly-researched aspect of experience which the study particularly set out to explore was the longer term perspective on practising mindfulness. The length of time many participants had been practising mindfulness, over 40% for more than two years, therefore formed a major strength.   It proved possible to speak with people who had attended Breathworks many years earlier, providing valuable insights into how mindfulness had become 'a way of life' for them, and the degree to which it had been integrated into their thinking and behaviour. The diary-based second interviews explored very recent, concrete experiences, and provided significant new insights into how mindfulness practice affected living with a LTC, both on a day-to-day and a longer-term basis. This was enhanced by including the experiences of Breathworks' trainers, who in most instances were 'experts' in both practising mindfulness and living with a LTC. Inclusion of MMBI trainers was another unique aspect of the study, developing the depth of insight into the mindfulness process and experience, and providing observations on many course participants who did not take part in this study. The rich data collected from participants enabled the development of the model of the experience of practising mindfulness with a LTC discussed in 10.2.

A significant limitation of this study was that certain sections of the population were underrepresented, notably those from minority ethnic communities, lower socio-economic groups and, to a lesser degree, men. While the demographic breakdown of participants was broadly representative of Breathworks participants, this does not accurately reflect national statistics regarding people with LTC.   This is a common problem in research into chronic illness (Thorne et al., 2002), and means that certain perspectives are missing which may challenge and change our understanding of chronic illness experience and the impact of mindfulness. The transferability of the findings from this study to the wider population of people with LTC is therefore unknown, and requires further exploration. In particular, more targeted recruitment strategies or specifically designed studies may be necessary to address this limitation and provide a more comprehensive perspective.

Despite efforts to target recruitment, the study also did not succeed in recruiting many people with negative or indifferent experiences of learning and practising mindfulness. The two participants who fell into this category, however, provided valuable insights into how this approach may not always be helpful or meet expectations, and a reminder that not everyone moves through the transition process to the same degree. This pattern of response was unsurprising, as people with less positive experiences are unlikely to be motivated to take part in research.   In this instance, recruitment from this group was further affected by Breathworks' database only containing details of people who completed the course. This precluded those who dropped out early due to negative experiences or dissatisfaction from taking part in the research. It is likely therefore that the experiences represented here are those of participants who have found mindfulness practice particularly life-changing or beneficial. This limitation needs to be borne in mind when considering the transferability of the findings. Observations from the trainers, and from those who did participate, suggest however that most people do gain a degree of

benefit, at least in the short term. Accessing participants who do not benefit presents a significant challenge, which would require a specifically designed study with targeted recruitment from a large population, as return rates would undoubtedly be extremely low.

A further limitation of the study was that the findings are based on participants' retrospective view of their journey with their LTC before and since practising mindfulness. This was an inevitable feature of the study design, which targeted people who had been practising for some time in order to gain insights into the longer term experiences of mindfulness practice. Data were also only collected over a relatively short period of time. Whilst recognising that all accounts are subjective, the lack of opportunity to follow participants through the process of change means the findings are based entirely on their reconstruction of the story of this journey. This limitation could be overcome to some degree with a long-term longitudinal study design with multiple data collection points, which would enable changes to be reported and observed as they were taking place.

Finally, whilst a coherent theoretical model of participants' experience of practising mindfulness with a LTC was developed using a grounded theory process, it did not prove possible within the time constraints of the PhD to construct a fully integrated grounded theory. As noted in 5.6.5.7, the core process was identified at the very end of writing up the findings. This allowed only limited opportunity for higher levels of theoretical integration within the analysis, which could not be developed through any additional data collection. There is therefore potential for further development of the model proposed here, which would *"pull together [the] theoretical scheme into the final grounded theory"* (Birks and Mills, 2011, p114). This could also be valuably strengthened and informed by recruitment of underrepresented participants (as described above), and integrating analysis of their data into the model.

10.3.2 Ensuring and demonstrating quality

A key strength of the PhD was the application of a set of criteria for ensuring quality in all aspects of the research process. As discussed in 4.6.1, the study drew particularly on the work of Charmaz (2006) and Meyrick (2006) to create a framework for ensuring quality, based on Charmaz's four criteria of credibility, originality, resonance and usefulness. The ways these criteria have been addressed will now be outlined.

10.3.2.1   Credibility

Although Charmaz addresses the need for credibility, I found Meyrick's approach, based on the principles of transparency and systematicity, more accessible and practical. She offers a range of ways to apply these principles to the research process (Meyrick, 2006) to ensure credibility. The following points highlight how these have been applied in this study.

- Chapter 4 provides a detailed account of my critical realist and feminist perspective and how these have informed the study design and analysis. From this interpretivist perspective, I believe findings are inevitably filtered through the 'lens' of the researcher.   An important aspect of ensuring quality was therefore making my own beliefs and experience as transparent as possible, and by reflecting on how they affected and have been affected by the research process

(Charmaz, 2004, Charmaz, 2006, Corbin and Strauss, 2008). This has been done through memo-writing throughout the study, and by inclusion of a reflexive chapter (Chapter 9) where these issues were explored in some detail.

- Meyrick (2006) recommends that researchers demonstrate credibility through making clear their aims and objectives, the methods selected to address them, and the rationale behind these decisions. A detailed description of all stages of the research process has been provided to ensure others can understand and follow the process of data collection and analysis, drawing on Sandelowski's (1986) recommended elements of an audit trail and the COREQ checklist of criteria for reporting on qualitative research (Tong et al., 2007).

- The inductive approach of GT means that it is important to demonstrate how the emerging theory is 'grounded' in the data, showing the links between data and conclusions (Meyrick, 2006). This has been done by including illustrative quotes from interview and focus group participants in the chapters 7 and 8 to support the findings. Aspects of the provisional findings were also explored with participants to ensure they remained grounded in the original data.

10.3.2.2 Originality

Charmaz encourages the researcher to consider what new insights their work offers, its social and theoretical relevance, and how their GT may *"challenge, extend, or refine current ideas, concepts, and practices"* (2006, p182). Also a key criterion for PhD research, the criterion of originality has been met in a number of ways:

- The study specifically addresses the lack of research into how practising mindfulness affected people's experiences of living with a LTC over the longer term, this having been identified as a gap in the literature. It therefore contributes to further understanding the effects of MMBIs in people's lives, and how these take place.

- The selection of Breathworks for the sample population enabled a little-researched intervention to be compared to MBSR and MBCT, contributing to identifying the common and differing experiences of learning mindfulness through different MMBIs.

- Breathworks' emphasis on kindness towards self and others has enabled the role of these attitudes in facilitating change and improved outcomes to be explored and clarified in greater depth. This study therefore offers a valuable contribution to a growing body of research into compassion (particularly self-compassion), mindfulness and health.

- The findings have been explored in relation to the wider context of the extensive literature regarding the chronic illness experience, in particular models of transition and shifting perspectives. This PhD significantly extends work in this area, highlighting the particular role of mindfulness in facilitating transition, and providing new insights into this process.

- Identifying the relationship of mindfulness to the transition process has also highlighted how practising mindfulness may facilitate effective and informed self-care, and provided insights into how it may contribute to this change through cultivation of awareness, acceptance and kindness.

- Participants' detailed and insightful accounts further understanding of the experience of living with a LTC. Morse notes that *"the long-term adaptation experience of the chronically ill […] can make them highly reflective respondents."* (2001, p320). This was enhanced in the PhD study by the non-judgemental observation and self-awareness developed through mindfulness and meditation.

10.3.2.3   Resonance

Resonance concerns how fully and deeply the research describes and gives further insights into the experience of participants. Charmaz (2006) asks the researcher to consider whether their GT offers participants or others in similar circumstances something that makes sense to them and provides *"deeper insights about their lives and worlds"* (2006, p183). These points were addressed in a number of ways.

During the interviews, I tried to clarify my understanding of people's experiences, often by reflecting back what I had heard. This frequently led to participants gaining a new and sometimes deeper perspective on their experience, demonstrated by comments such as *"I've never thought about it before but…"*. The second interviews provided a particular opportunity to explore resonance through asking participants to engage with and respond to my developing ideas (Charmaz, 2001). Discussion of the draft 'model' of the mindfulness experience revealed that participants 'recognised themselves' and sometimes also found the model clarified and gave further insights into their experience. This process of exploration continued in the focus groups. Finally, some participants found keeping a diary for a week gave new insights into their behaviour and habits, as well as revealing how mindfulness had become integrated into their lives. In this way the research helped to uncover *"taken-for-granted meanings"* (Charmaz, 2006, p182), bringing what had often become 'second nature' into consciousness.

10.3.2.4   Usefulness

The usefulness of research concerns how applicable its findings are to people's everyday lives, how it builds on existing knowledge and what directions for future research it identifies. (2006), This was a key concern for me and to many of the study participants, who hoped their participation would help raise awareness and understanding of mindfulness with a wider audience. This gave me an added sense of responsibility to ensure my findings were 'useful'. The study findings indicate that mindfulness has a broad range of potential application in the lives of people with LTCs. They also offer a detailed understanding of how participants used mindfulness and applied it to their *"everyday worlds"* (Charmaz, 2006, p183), and of the differences this made to their lives. The contribution of the PhD to existing knowledge has been identified earlier in this chapter, and recommendations for future research are outlined below.   A strategy for dissemination of the findings is also being developed to ensure key information is made available to potential users of mindfulness and those who may refer people to MMBIs.

10.3.3 Implications for policy, practice and future research

10.3.3.1 How this research informs clinical practice

The study confirms existing research, explored through the overview and review of qualitative studies, which suggests that MMBIs have wide application across a range of both physical and mental health LTCs, and offer potential to significantly benefit many people. They may offer some relief of symptoms but, perhaps more importantly, they provide skills and attitudes to enable a wider range of people to manage their illness effectively, to both take account of its impact and to keep it in perspective within their wider lives and selves. Mindfulness may be of particular benefit to people who have struggled to come to terms with their condition and who are open to making a commitment to trying a new approach. The emphasis on kindness within MMBIs, particularly Breathworks, may mean they are especially valuable for people with strongly self-critical attitudes and behaviours which affect their ability to manage their condition effectively. As with many interventions, identifying who is 'ready' to benefit remains a challenge, but it is also possible that for some people, the process of participating may move them nearer to such 'readiness'.

This research has particularly explored how people integrate mindfulness into their everyday lives, and suggests that it makes them very skilled and responsive in managing their conditions. Their high level of self-awareness and self-directedness, defined by Koch et al (2004) as a 'Self-Agency model of self-management' may mean that they are not always 'compliant' with standard regimes of treatment, and that they are clear and specific in their requests for support from healthcare professionals. These qualities may at times present challenges to those professionals who are uncomfortable with the reality of empowered patients. This dynamic was highlighted in 10.2.3.3 in relation to transition experiences, but has also been discussed more widely as an issue in chronic disease management, where healthcare practitioners' vision of shared decision-making was often not reflected in their practice (Paterson, 2001a). The introduction of mindfulness training into healthcare settings may therefore prompt further challenges to referrers and participants, as well as offering benefits.

The research also confirms how people's lives are profoundly affected by living with a LTC on many levels, a point which is emphasised in much of the chronic illness literature. Toye et al's (2013) work highlights the significance of healthcare professionals' attitudes in helping people come to terms with their changed reality, and of the need to recognise the fundamental changes in identity and experience that they may be struggling to accommodate. The PhD study's findings confirm this point, and also the need to recognise the degree to which, with appropriate support and resources, many people <u>can</u> make a transition and learn to live well with illness.

10.3.3.2 How this research informs mindfulness training

The study findings suggest that Breathworks' Living Well with Pain and Illness' course offers a valuable alternative intervention to MBSR and MBCT, producing many similar changes in people's experiences of living with a LTC. They also highlight the particularly valuable role of an emphasis on kindness within the training, and how this enables

participants to engage with the challenges of mindfulness practice. This may be an element which other MMBIs could beneficially pay greater attention to within their programme.

Participants' detailed accounts of practising mindfulness suggest that different practices and approaches may be of benefit to people with different conditions or experiencing particular challenges. For example, kindly awareness appeared to be valuable in dealing with difficult people, breathing meditations sometimes seemed to boost energy in contrast to the calming effects of the body scan, whilst informal practices such as paying attention to immediate activities or surroundings were sometimes valuable at times of overwhelming emotion. Whilst these are tentative findings, they reinforce the value of Breathworks' 'toolbox' concept and suggest ways in which it could be developed: introducing participants to a range of approaches and encouraging them to select or focus on what 'works' for them, but in addition reinforcing this message by offering suggestions from others' experience to guide and support those choices.

10.3.3.3   Directions for future research

The pivotal role of kindness in enabling some people's practice of mindfulness has been highlighted in this study, and this supports a growing body of recent work which suggests the importance of self-compassion within the process of change. This is a complex area, which needs further exploration and clarification through a range of approaches, including comparisons of outcomes from mindfulness-based and compassion-based interventions using both quantitative and qualitative methodologies.

The varying patterns of mindfulness practice identified in this study highlight the need for additional research into the relationship between these different approaches to practice and outcomes, and the expectations and needs of participants. These are complex issues, raising questions about the depth and dimensions of change which are possible through mindfulness practice.

An area of change highlighted more clearly than in previous studies was the benefits that participants' practising mindfulness had on those around them, particularly family and friends. Whilst learning mindfulness directly may well offer these benefits, it would be valuable to further explore these indirect effects of mindfulness, particularly on those with caring responsibilities, whose lives are often significantly impacted.

The understanding of mindfulness as a facilitator of transition prompts questions about whether it may have a role to play with people experiencing types of transition other than learning to live with a LTC. Thus, further research could explore how learning and practising mindfulness, adapted to the particular groups' needs, could support refugee and other migrant groups, people who have experienced losses such as bereavement, unemployment or who are facing the challenges of ageing.

The associations between mindfulness, transition and self-care also need further exploration. If mindfulness is an important facilitator of self-care for people with LTC, as these findings suggest, there is a need to consider its incorporation into existing self-management programmes and to research the effects this may have on a range of relevant

outcomes. This needs to include exploration of how any changes in people's approach to their self-care impacts on their relationships with health professionals.

The difficulty in recruiting participants who have not found mindfulness helpful means that these experiences are still not fully understood. Targeted research exploring negative cases would help to refine and extend the applicability of the theoretical model developed in this study. Such research would also enable the barriers to participation and engagement to be explored, and help to identify whether and/or how these can be overcome. It would also further clarify who is likely to benefit from mindfulness, which will facilitate appropriate referral to MMBIs.

The underrepresentation of people from minority ethnic groups within the study echoes that seen in other research into MMBIs, and into experiences of living with a LTC (Thorne et al., 2002). This highlights the need for further exploration of how learning and practising mindfulness is experienced by people with LTCs in these communities. This particularly applies to Buddhist and Hindu traditions, where aspects of mindfulness such as acceptance and meditation are more familiar values and practices, and where there is some suggestion that the westernisation of MMBIs has made them less accessible than more traditional approaches (Hall et al., 2011). For other religious traditions, there is a need to explore whether the Buddhist origins act as a barrier to participation. This area needs further exploration through specifically targeted studies, and is part of a wider debate about the separation of mindfulness from its spiritual roots.

10.4 Conclusion

Through this study, I have explored how practising mindfulness affected people's experiences of living with a LTC, in particular the changes which took place over the longer term, and the ways that mindfulness became integrated into their lives. The analysis of the qualitative findings led to the identification of a theoretical model of the changes in people's experiences, integrated around a core process of '*Starting where I am'.* As noted in 10.3.1, there is potential to develop this model through further theoretical integration to generate a full grounded theory. In addition, the lack of representativeness of the sample, particularly with respect to populations from ethnic minority and lower socio-economic groups or with negative experiences of mindfulness, means that the transferability of the findings to a wider population remains to be explored.

Within these limitations, the model highlighted how mindfulness enabled people with a diversity of LTCs to become aware of and accept the reality of their situation in all its complexity, both its difficulties and its pleasures, and to respond appropriately to it. Through a combination of a changed relationship to their illness, new resources and confidence, and more responsive patterns of living, participants learnt to accommodate their LTC in their lives, both practically and emotionally. They were more 'tuned-in' to their needs, and adjusted their behaviour in both the immediate and longer term as a result. The study also offered new insight into how people benefited from shifting their focus from the *outcomes* of their actions, which were outside their control, to the *process* of living with and responding to their condition, which was within their control. These

changed ways of thinking and acting were sometimes challenging and hard to sustain, but the benefits they gained helped motivate them to continue. The findings offered new insights into the diversity of ways in which people made mindfulness a part of everyday life, and how their choices and patterns of practice appeared to relate to different needs, expectations and perceived benefits.

This study has distinctively identified the role of cultivating kindness and compassion, particularly towards oneself, in supporting both the process and outcomes of mindfulness practice. It contributes to a growing body of research into this topic, and its exploration was facilitated by the selection of Breathworks' MMBI for the qualitative study sample, an intervention which places particular emphasis on developing kindly awareness. Kindness was highlighted as helping people to develop a greater sense of self-worth and to pay more attention to their own self-care, potentially contributing to the positive outcomes which motivated continued practice. It had a pivotal role for some people in facilitating their application of mindfulness to living with their LTC.

Practising mindfulness facilitated and supported sometimes profound changes in people's experience of living with a LTC. These changes seem to correspond to the characteristics of transition, which identifies the process by which people may come to terms with life-altering experiences. Practising mindfulness appears to be a potentially powerful facilitator of transition, enabling people to reshape their identity and behaviour. Participants' accounts of ongoing change and adjustment to their condition also confirmed the complex and non-linear nature of the transition process. Similar patterns of change were evidenced across all conditions, including both physical and mental health problems. This suggests that models of living with LTC, such as transition, which have only been applied to physical illness experiences, may have wider application.

One way in which transition has been found to be apparent is in people's patterns of self-care, in particular through moving to becoming more confident and self-directed. The study findings showed that mindfulness, by facilitating people's awareness and understanding of their illness and wider experience, directly supported such an approach. It also fostered a holistic understanding of illness and its effects, helping people balance their competing needs and live as fully as possible. This may offer a challenge to healthcare professionals, whose focus is often on disease-specific aspects of illness and encouraging compliance with treatment regimes. Equally, people's clearer insights and understanding of their condition, and more open and optimistic attitude to their lives, may enable them to act as informed and inspiring partners in the management of their care, demonstrating the benefits of practising mindfulness in coping with the significant and ongoing challenges of living with a LTC.

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Appendix A: Search strategies and results for overview

[Searches undertaken November 2013]

Medline (via Ovid) search

1	mindfulness*.mp	1434
2	meditation .mp or exp Meditation/	2205
3	mindfulness-based.mp	601
4	1 or 2 or 3	2964
5	exp Review/ or review.mp	1614920
6	4 and 5	588
7	Filter by year 2004 – current	487

EMBASE (via Ovid) search

1	mindfulness*.mp	2462
2	mindfulness-based.mp	1032
3	meditation .mp or exp Meditation/	4130
4	1 or 2 or 3	5614
5	exp Review/ or review.mp	2014380
6	4 and 5	1358
7	Filter by year 2004 – current	1036

AMED (via Ovid) search

1	mindfulness*.mp	187
2	meditation .mp	539
3	mindfulness-based.mp	79
4	1 or 2 or 3	647
5	exp Review/ or review.mp	13570
6	4 and 5	61
7	Filter by year 2004 – current	38

PsychINFO (via Ovid) search

1	mindfulness*.mp or exp Mindfulness/	2717
2	meditation .mp or exp Meditation/	4097
3	mindfulness-based.mp	1215
4	1 or 2 or 3	5796
5	exp Literature Review/ or review.mp	158546
6	4 and 5	840
7	Filter by year 2004 – current	802

CINAHL search   (MH = subject heading)

1	mindfulness-based = keyword	312
2	meditation = (MH) or keyword	2050
3	mindfulness = keyword	829
4	1 or 2 or 3	2510
5	Cochrane library (MH) or systematic review (MH) or literature review (MH) or review = keyword	183362
6	4 and 5	215
7	Limit date to 2004 – 2013	180

CENTRAL (via Cochrane Library) search

1 "mindfulness" in title, abstract or keywords, date limited to 2004-2013
2 Searched Cochrane Reviews (1) and Other Reviews (28) within retrieved results
3 "meditation" in title, abstract or keywords , date limited to 2004-2013
4 Searched Cochrane Reviews (8) and Other Reviews (26) within retrieved results

Web of Science search

1	topic = mindfulness and date limit 2004 - current	2942
2	topic = mindfulness-based and date limit 2004 – current	850
3	topic = meditation and date limit 2004 - current	3645
4	1 or 2 or 3	5509
5	topic = review and date limit 2004 – current	830611
6	4 and 5	510

Appendix B: Recruitment mailing for Breathworks graduates

September 2011

Dear Breathworks graduate,

I hope you are well and managing your pain and life as best as you can.

Research is very important to us at Breathworks, as it helps us to find out more about how effective our programmes are, and what we can do to improve what we do. Living with a long term condition is a challenge many of us face every day, and we are always looking to find ways of developing our work so that it helps more people to live in more fulfilled and happier ways. I hope this has been your experience since attending the "Living Well with Pain and Illness course".

Over the past few years, we have worked with a number of people who have been researching Breathworks and mindfulness meditation, and this has led to the publication of important findings of the benefits of our work. I'm therefore really pleased to support this latest piece of research which is being done by Jaqui Long, a PhD student at Leeds University. She is going to be looking at the longer term effects of learning mindfulness meditation, and at how people make use of what they learn in their everyday lives. I'm sure this is going to give us lots of useful and important information, especially about exactly how mindfulness helps people to live with long term conditions.

The rest of the information in this mailing is from Jaqui, but is being sent out by Breathworks to protect your confidentiality. If you want to get involved, please contact Jaqui directly – we at Breathworks won't know whether or not you decide to participate. But I am writing this cover letter to endorse Jaqui's work and to express my gratitude to her for wanting to help deepen and broaden the Breathworks' research base and to encourage you to participate if you are at all interested.

Thanks for your time.

With best wishes

Vidyamala

September 2011

Dear Breathworks graduate,

Invitation to participate in research into mindfulness meditation and long-term conditions

I am a PhD student at the University of Leeds, and I am looking at how mindfulness meditation affects people's experiences of a living with a long term condition.

As part of this research I want to talk to people who have attended Breathworks "Living Well with Pain and Illness" course. I understand that you participated in this course some time ago, which is why you are receiving this letter. However, please note that I have not been given access to any personal information about you, and this mailing is being sent via Breathworks to maintain confidentiality.

To explain briefly, I am interested in hearing from people who have a long term health condition and have attended at least half of the Breathworks course. I want to talk both to people who have found mindfulness meditation techniques helpful <u>and</u> those who haven't, as all this information will help us understand more about if and when it is beneficial. There are two ways in which you can participate in the study, either through individual interviews or focus group meetings or both.

The enclosed information gives details of the research and will hopefully answer any questions you have. However, please contact me if you would like to know more before you decide. If you are interested in taking part please complete the reply slip, or contact me by phone **(0113 343 7175)** or email **(hcjal@leeds.ac.uk)**. I will then be in touch to discuss things further. No-one at Breathworks will be told whether you decide to take part or not, and no information will be shared which could identify you to Breathworks staff.

Thanks for taking the time to read this letter, and I look forward to hearing from you.

Yours sincerely,

Jaqui Long

PS   We are aware that some people have already taken part in other research projects. We want to give everyone the chance to participate in this study but please don't feel that you have to - we will not tell anyone what you decide to do.

> **Please let me know if you would like this material in larger print or electronic format.**

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INFORMATION ABOUT THE RESEARCH

Mindfulness meditation and living with a long term condition

We hope you will be interested in taking part in this study. Before you decide, we would like you to understand why the research is being done and what it would involve.
- Please read this information carefully **(contact us if you would prefer a larger print or electronic copy).**
- Discuss it with others if you wish.
- Ask us if there is anything that is not clear or you want to know more about.
- Take your time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of this study?

There is a growing interest in how mindfulness meditation programmes like Breathworks can benefit people with long-term physical and mental health problems. A number of studies have identified improvements in people's symptoms (e.g. pain, stress and depression) after learning mindfulness meditation. However, there is still a lot we don't know.

In this study we want to find out more about the following questions:
- What are the longer term effects of practising mindfulness meditation?
- In what ways do people benefit and what kind of experiences do they have?
- Who does and doesn't benefit from practising mindfulness meditation?
- Which conditions or symptoms is it most helpful for?

Why have I been asked to participate?

We are sending this information to everyone who has participated in the Breathworks "Living Well with Pain and Illness" programme in Manchester, Bradford and Leeds. However, for this study we specifically want to talk to people who meet the following criteria:
- Consider themselves to have a long-term physical or mental health condition. (This doesn't need to be diagnosed by a doctor, and there won't be a medical assessment.)
- Started a Breathworks course at least 6 months ago
- Attended at least half of the course sessions (4 or more)

We don't have any personal information about you so you will need to decide if you meet these criteria. If you are not sure, please contact us to discuss any questions in confidence. You can still decide not to take part after contacting us.

Do I have to take part? What if I change my mind?

It is entirely up to you to decide. You won't be put under any pressure and no-one apart from the research team will know if you take part or not – Breathworks staff won't be told what you do. If you choose to take part, we will contact you and give you more

information. You will also be asked to sign a consent form, but you can still change your mind after this.

You can withdraw from the study at any time and you do not have to give us a reason. If you decide to withdraw, or become unwell and unable to participate further, we will still include the information you have already given us in the study, unless you ask us not to.

What will I have to do if I take part?

There are two phases to the study. You can choose to take part in one or both parts, so long as you are eligible to do so – see below for details.

Option 1: Interviews

In this phase we want to get a detailed understanding of people's experiences. You would be asked to take part in 2 interviews approximately 3 months apart and to complete a diary for one week just before the second interview. This would work like this:

> **First interview** (1.5-2 hours). I'll start by answering any questions about the study and asking you to sign a consent form. We'll talk about your health and its effects on your life, and about learning and using mindfulness meditation. I'll then explain what happens next and about the diary.

3 months later…

> **Keep a diary** about your experiences for 1 week. This need not take up much time - you can choose how much and how often to write. You won't need to change what you do in any other way. Most of the diary won't be seen by anyone – it's to help you think what to talk about in the second interview.

1 week later…

> **Second interview** (1.5-2 hours). We'll talk about some of the experiences you recorded in the diary, and about your experiences – if any - of mindfulness meditation and its effects on your life. I'll collect the part of the diary where you recorded any mindfulness practice during the week.

If you want to take part in the interviews, you'll need to have tried using the mindfulness techniques since you attended the course. But you DON'T need to have found it helpful – we want to hear about both positive and negative experiences.

- If the interview time seems too long to manage in one session, we can arrange to have a break part way through or split it into two parts on different days.
- Interviews will take place in your home, or at another convenient location. Unfortunately we don't have funding to pay travel expenses to attend interviews.
- You can complete the diary in either paper or electronic form.
- We won't ask to see it, except for the record of any mindfulness practice you do.
- The interviews will be audio recorded so they can be typed up accurately afterwards. You can see a copy of the transcript if you wish.

Option 2: Focus Groups

Once the interviews have been completed, we want to discuss the results with a wider group of people with different experiences who are interested in mindfulness meditation. This will help make the study more detailed and relevant. To do this we will be running a number of focus group meetings.

> **Focus group** (one meeting of up to 2 hours). We'll ask you for your thoughts and feelings about a number of questions relating to mindfulness meditation and living with a long term condition.

You do NOT need to have been using mindfulness techniques since the course to take part in the focus groups.

- Meetings will be held at a number of accessible locations to suit participants.
- We hope to be able to reimburse travel expenses for attending the meeting but cannot guarantee it at this stage.
- The meetings will be audio recorded in the same way as the interviews.
- NB: Focus groups will not take place until later in the study (early 2012), so you will not be invited to participate for some time if you are only taking part in this stage.

What are the benefits and disadvantages of taking part?

- Many people find it helpful to think and talk about their experiences.
- We also hope the information we get will help us understand more about who benefits from mindfulness meditation and in what ways. This will help make it available to the right people in the future.

- We will be asking you to give some of your time to the study, as described in the previous section.
- Talking about personal experiences such as health problems can also sometimes be difficult or upsetting. We will help you to find appropriate support if you feel you need this, and you are free to withdraw at any time.

Will the information I give be kept confidential?

Confidentiality is an important issue, particularly when people are sharing personal information. We will ensure that your privacy and identity is protected at all times.

- Electronic information will be stored on a password protected computer, and paper copies kept in a locked filing cabinet that only the research team will have access to.
- Any quotes used in publications will be anonymised by giving you a pseudonym, so that you cannot be identified.
- Comments you make about your experience of Breathworks will be anonymised, so you cannot be personally identified by the organisation.
- All data will be destroyed 2 years after the study has been completed.

Very occasionally, there may be a concern that a participant or someone they know is at risk. In this situation it may be necessary to pass on information to someone outside the research team. We would let you know if we were going to do this.

What will happen to the results of the study?

This material will form a key part of the lead researcher's PhD thesis, which will be published at the end of the study in 2012. We will keep you updated on the progress of the study during this time and give you information about the findings when it is completed.

Findings from the study will be presented at conferences and submitted to relevant journals. We also hope to share information with people who may be interested in mindfulness meditation, including healthcare professionals and organisations working with people with long-term health conditions. The study will be made available to Breathworks, who may use it to improve their programme and – if the findings are positive – to promote their work.

Who is the study being done by? Who has approved it?

The study is funded and organised by the School of Healthcare at the University of Leeds (see contact details). The lead researcher is Jaqui Long, who is undertaking this work as part of her PhD study, under the supervision of Dr Michelle Briggs and Dr Felicity Astin.

The study has been reviewed and approved by Leeds Central Research Ethics Committee. This ensures that the work is carried out to the required standards to protect your interests.

What if there is a problem?

If you feel unhappy with the process at any time, you may raise your concerns with the researcher. Should you have a complaint about the research and the way it is being conducted, please contact her supervisor, Dr Michelle Briggs (0113 343 6885 m.briggs@leeds.ac.uk) or the Faculty Head of Research Support, Ms Clare Skinner (0113 343 4897 c.e.skinner@leeds.ac.uk).

How do I get involved?

- **If you want to take part**, fill in the reply form and return it to Jaqui Long at the address below. Or you can phone or email with your details.
- **If you want more information** or have any questions or concerns about the study please phone or email Jaqui using the following contact details:

Jaqui Long, School of Healthcare, Baines Wing, University of Leeds, LS2 9JT

Tel: 0113 343 7175 Email: hcjal@leeds.ac.uk

Thank you for taking the time to read this information sheet.

[NB Similar sets of materials (not included) were produced for recruitment of trainers and founders]

Appendix C: Additional targeted recruitment information for second phase mailing

RESEARCH UPDATE – SEPTEMBER 2011

We are now half way through the interviews for this research project, and have already gathered lots of really interesting and valuable stories from people with different experiences, conditions and backgrounds. We do want to make sure we talk to as wide a range of people as possible, so that everyone's point of view is included. **We'd be particularly interested to hear from you if you've had any of these experiences:**

- Did you find the mindfulness meditation and mindfulness practice you learnt at Breathworks unhelpful, or not very helpful to you?
- Do you have a religious belief or practice other than Buddhism e.g. Christianity, Islam, Judaism? Has this influenced your experience of Breathworks and mindfulness meditation?
- Do you have no belief or interest in religion or spirituality? Has this influenced your experience of Breathworks and mindfulness meditation?

Please don't be put off from responding whatever your experience is, but as our time and resources are limited, we may not be able to involve everyone who replies. Once we receive your reply, we'll get in touch with you by phone to find out a bit more about your experience, and will then be able to let you know if we need to interview you, or if there's any other way that you can take part in the research.

Thanks for your time.

Appendix D: Socio-demographic data collection form

Participant information

Gender	Male		Female	
Ethnicity	White – British		Asian or Asian British – Other	
	White – Irish		Chinese	
	White - Scottish		Gypsy/traveller	
	White – Other		Mixed - White and Black Caribbean	
	Black or Black British – Caribbean		Mixed - White and Black African	
	Black or Black British – African		Mixed - White and Asian	
	Black or Black British – Other		Other Mixed background	
	Asian or Asian British - Indian		Other Ethnic background	
	Asian or Asian British - Pakistani		Not Known	
	Asian or Asian British - Bangladeshi			
Age	16-25		46-55	
	26-35		56-65	
	36-45		66+	
Highest educational qualification	e.g. GCSE, BTEC, Degree			
Marital status	Living alone			
	Married or living with partner/cohabiting			
	Living with friends			
	Other			
Current occupation				
Previous occupation				
Religion/ belief	Buddhist		Muslim	
	Christian		Sikh	
	Hindu		Other	
	Jewish		None	
Meditation experience before Breathworks	Never done any		Some experience	
	A little experience		Was already regularly meditating	

Appendix E: Consent form

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Study title: Mindfulness meditation and living with a long-term condition
Name of researcher: Jaqui Long

Please read each statement carefully and initial in the box next to it to show that you have understood and agree with what is said.

I have read and understood the participant information sheet…………………….....

I have had the opportunity to ask questions and discuss this study, and have received satisfactory answers to all my questions……………………………………..

I understand that my participation in the study is voluntary and I am free to withdraw from the study at any time without having to give a reason………………..

I agree that if I withdraw from the study or am no longer able to consent to participate, the information I have given can continue to be used within the study…

I understand that interviews and focus groups will be audio recorded and I agree to this being done……………………………………………………………………

I understand that any information I give may be included in published documents but my identity will be protected by the use of pseudonyms…………………………

I understand that all the information I give will remain confidential unless it is considered that someone is at risk of serious harm, in which case information will be passed on to an appropriate person…………………………………………

I understand that any information I provide will be stored securely and only accessed by those carrying out the study……………………………………………..

I agree to take part in this study……………………………………………………………

Name of participant …………………………..   Signature …………………………….

Date …………..

Name of researcher ………………………….   Signature …………………………….

Date …………..

Thank you for agreeing to take part in this study.

Appendix F: First interview schedule

1.   Introductions:
• Explain interview, answer any questions
• Consent form signed
• Reminder re recording, limits of confidentiality
• Collect demographic information

2.   Main Questions
a)   Health experience
        Introduce:
I'd like us to start by talking about your health and how it affects you.

Main question:
Can you tell me something about your health history and what it is that you're living with now?

Prompts:
• How long have you had condition(s)?
• What symptoms? Treatments?
• Does it affect you all the time? Is there much variation?
• What is about the condition(s) that affect you most?

Main question:
In what ways does all this affect different areas of your life?

Prompts:
• Work
• Relationships
• Everyday functioning
• Mood
• Sense of self/identity?

Transitional question:
• Were there particular health issues that prompted you to attend Breathworks?

b)   Breathworks experience
        Introduce:
I'd like to talk now about your experience of Breathworks.

Main question:
Please tell me about your experience of attending the Breathworks course.

Prompts:
• When did you attend?
• Why did you decide to attend? What were your expectations?
• Any particular positive or negative aspects of the experience? Why?
• What was your experience of the different meditation practices?
• How did you find the experience of the group?
• What effects did it have on you at that time, if any?

Main question:
What experiences have you had with mindfulness meditation and practice since the course?

Prompts
• Have you continued any kind of practice? Regular/irregular/not at all?
• Any particular things from the course you have found helpful? Not helpful? Why?
• Have you maintained any contact with Breathworks since the training? Why?

Main question:
Have you noticed any changes in your experience since attending Breathworks?
We will cover this in more depth in next interview, but I'd be interested in any initial thoughts you have about this.

3. Ending/Next steps:
• Introduce diary:
a) purpose – to understand more particular experiences of mindfulness in everyday life with a long term condition

b) two sections - what will be handed in and what won't

c) using section 2 - as aide memoir, no need to record a lot, share only what you want, not for anyone else's benefit

d) timing - when to complete – week leading up to 2nd interview

e) how to complete – offer electronic version, dictaphone

• Second interview – purpose, arrange provisional date

• Thanks, any questions

Appendix G: Diary

This information shows the front page, guidance sheet and two sections for completion each day. Section 1 records mindfulness practice, Section 2 was an aide-memoir to prompt discussion at second interviews.

DIARY:

A week in the life of….

Name	
Start date:	
End date:	

HOW TO USE THE DIARY

What should I write about?

- **Section 1:** We'd like you to make a note each day of whether you do any formal or informal mindfulness practice (see the diary sheet for details). There's no right or wrong answer to this question! You don't need to change what you do - we're interested in what's normal for you, which may vary from day to day. This section will be collected in as part of the research.

- **Section 2:** This if for you to write about situations during the week where mindfulness has had an effect on what you do, feel or think, particularly in relation to your health. This can be simple, everyday things (e.g. opening a can of beans, making a phone call) or bigger events (e.g. discussing treatment options with a doctor, doing something challenging). They could be 'positive' or 'negative' experiences. This section is for your own thoughts and will not be collected in.

How much do I need to write?

- Please try to fill in Section 1 every day.
- You can write as much or little as you want in Section 2 - this is just something to help you think what to talk about at the second interview.
- Don't try and record everything! You might want to choose one thing in your day that seems relevant or significant. You might just want to write a few words or draw a picture to remind you of something.
- It doesn't matter if you don't write about something every day.

Who will see what I have written?

- The information in Section 1 will be seen by the research team and may be used anonymously in the final report and other research publications.
- The rest of the information won't be seen by anyone else unless you choose to share it at the second interview.

What do I do with the diary when I've finished it?

- Bring the diary to the second interview. We'll talk about what you have written, but you can choose which things to share.
- We'll ask you to hand in Section 1 – the rest is yours to keep.

Thank you for your help with this research.

If you have any other questions, please contact Jaqui Long on 0113 343 7175, email hcjal@leeds.ac.uk

SECTION 1: RECORD OF MINDFULNESS PRACTICE

Please make a note each day this week of any mindfulness practice that you do. We will ask you to hand in this record at the second interview. Thank you.

DAY 1: Did you do any kind of mindfulness practice today?   YES / NO

---

a) Formal practice (sitting or walking meditation, body scan etc)?

YES / NO

If YES – what did you do?

For how long?

---

b) Informal practice (using mindfulness in everyday life e.g. washing up,

breathing)? YES / NO

If YES – what did you do?

For how long (if it's possible to measure this)?

Participant code number:

SECTION 2: DIARY

DAY 1	Date:

What happened today?

Some questions that might help get you started:

- Has there been any particular situation or event today when your condition has affected what you have done, thought or felt?
- What happened? How did you deal with it or respond to it? Has mindfulness played any part in this experience? If so, in what way?
- If you did any kind of mindfulness activity, did this have any effect on your day? If so, what did you notice?

Appendix H: Second interview questions

1.   Introductions:
•   Reminder re recording
•   Catching up – how has life been since met?
•   Diary – feedback on completing it – did they use it? What was the experience like?

2.   Record of mindfulness practice for past week:
•   Experience of past week: How typical of life? How similar/different to 'usual'?
•   What keeps you going with your practice? Is it fairly constant or do you have lapses and then come back? What causes lapses? What brings you back? Q2

3.   Specific experiences related to health/LTC over the past week
a)   If diary has been completed:
Choose an experience you wrote something about where you feel mindfulness, particularly meditation, affected your experience, for us to talk about in more detail?

b)   If diary has not been completed:
Think about your last week, and tell me about something that happened where you feel mindfulness, particularly meditation, affected your experience?

Explore:
•   What happened?
•   What was that experience like? Thoughts, feelings, sensations?
•   How did mindfulness influence this experience? What was different to how it might have been before you learnt this? Q1, 2, 3
•   How do you think it has these effects? What happens? Q1, 3

May do a couple of these experiences depending on how much people have to say.
Keep in mind:
•   Management of condition
•   Symptoms/condition
•   Impact of health on life
•   Perceptions of self: health/wellbeing, condition, identity – how look at self and LTC
•   Relationships with others: communication of condition, needs etc

4.   General experiences
•   Is this/are these a common or typical way in which you might use MM? Q2
•   Are there other times where you will particularly use MM to help you? Q2
•   Are there times when you try to use it and it doesn't help? Q1, 4, 5
•   Does it ever make things worse? Q1, 4, 5
•   Has your experience of using it changed over time? With practice? Q1, 3

5.   Overview, clarifying role of MM in the whole experience
•   Overall, in what ways is your experience of living with your health condition different as a result of using mindfulness, particularly the meditation?
•   How has MM changed the way that you look at your illness/condition, how you make sense of it in your life?
•   What specific role do you think the mindfulness meditation has to play in your whole experience (not easy to separate)? Do you think it would be enough on its own?

•   How would it be different if it didn't include the ideas around kindness? Is this important to the way you use MM?

6.   Ending

•   Thanks, any questions
•   What will happen next – ask if want to receive updates: email/post
•   Explain that summary information will be sent at end of study, possible feedback meeting
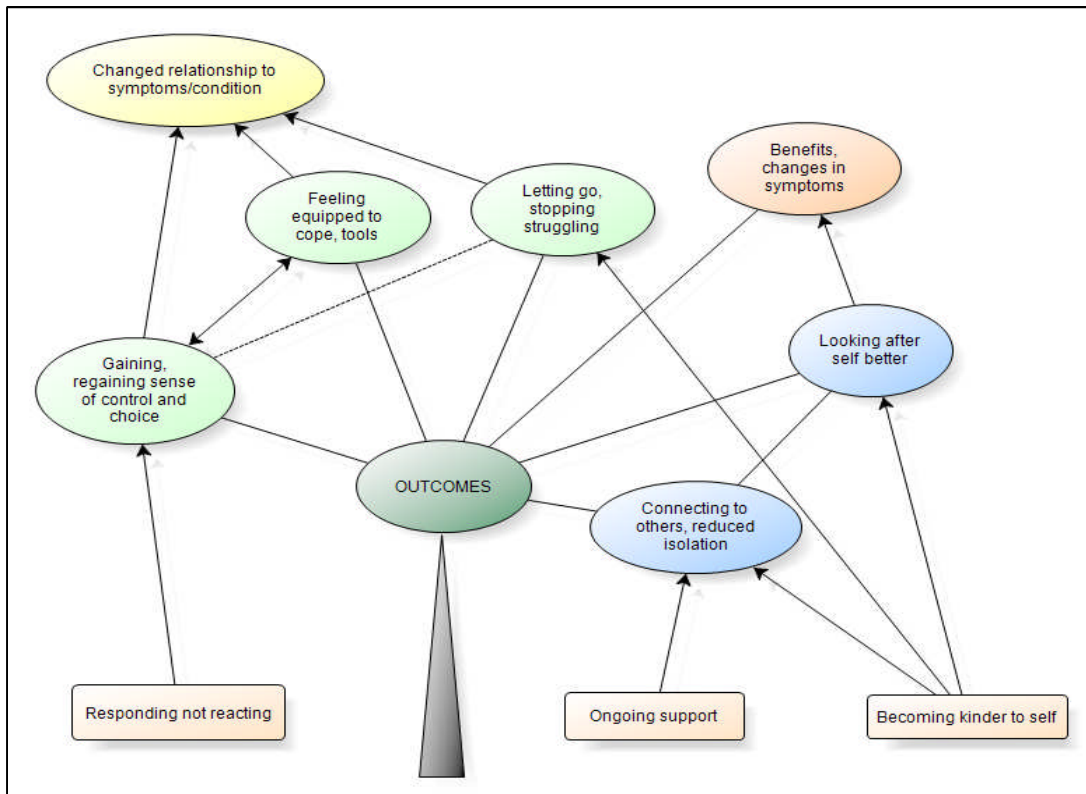•   Give brief summary of findings so far

Appendix I: First draft of mindfulness model

These diagrams form the first draft of a model of the mindfulness experience based on the analysis of the first interviews, which was discussed at second interviews.
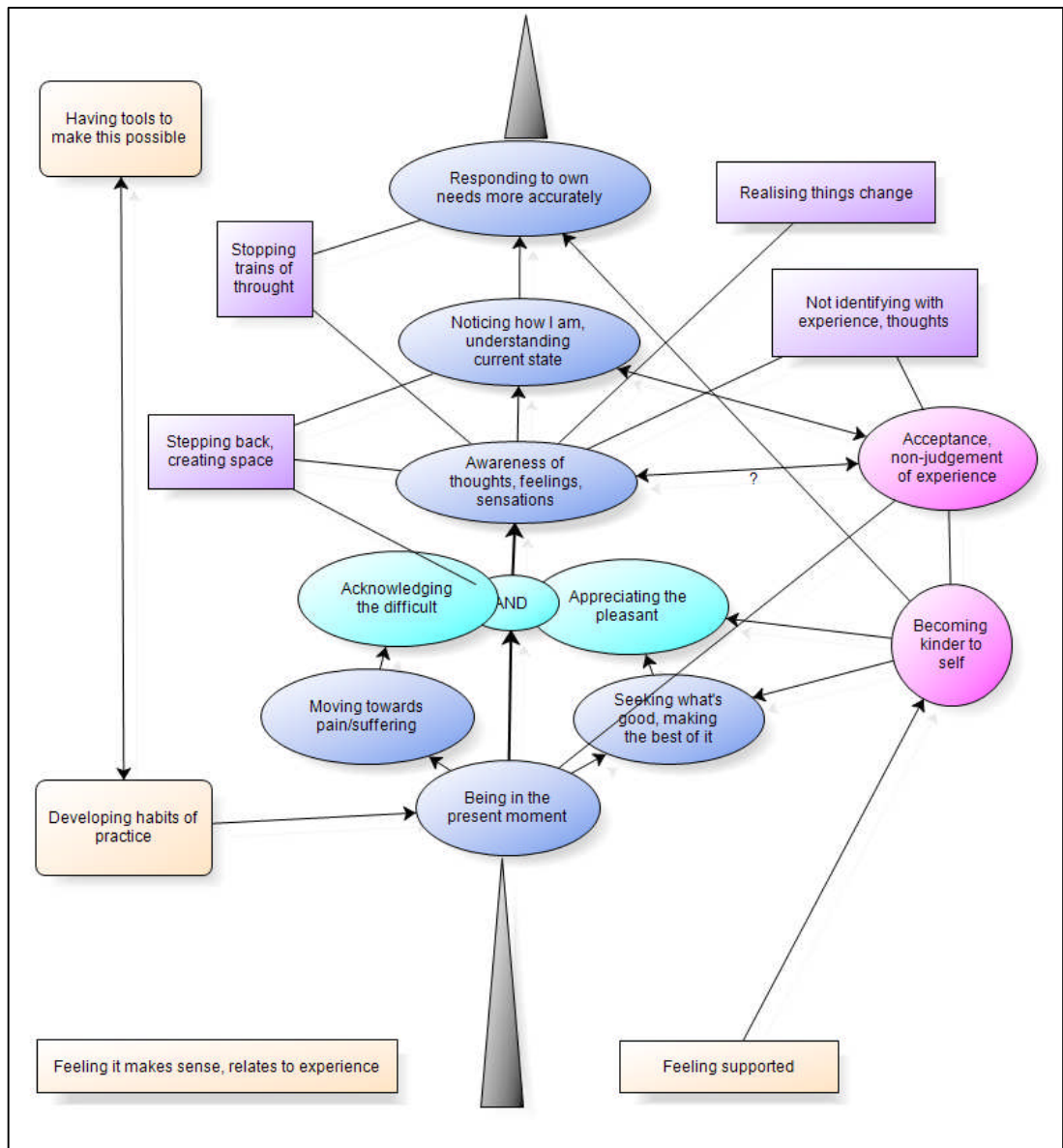
Part 1: Underpinnings
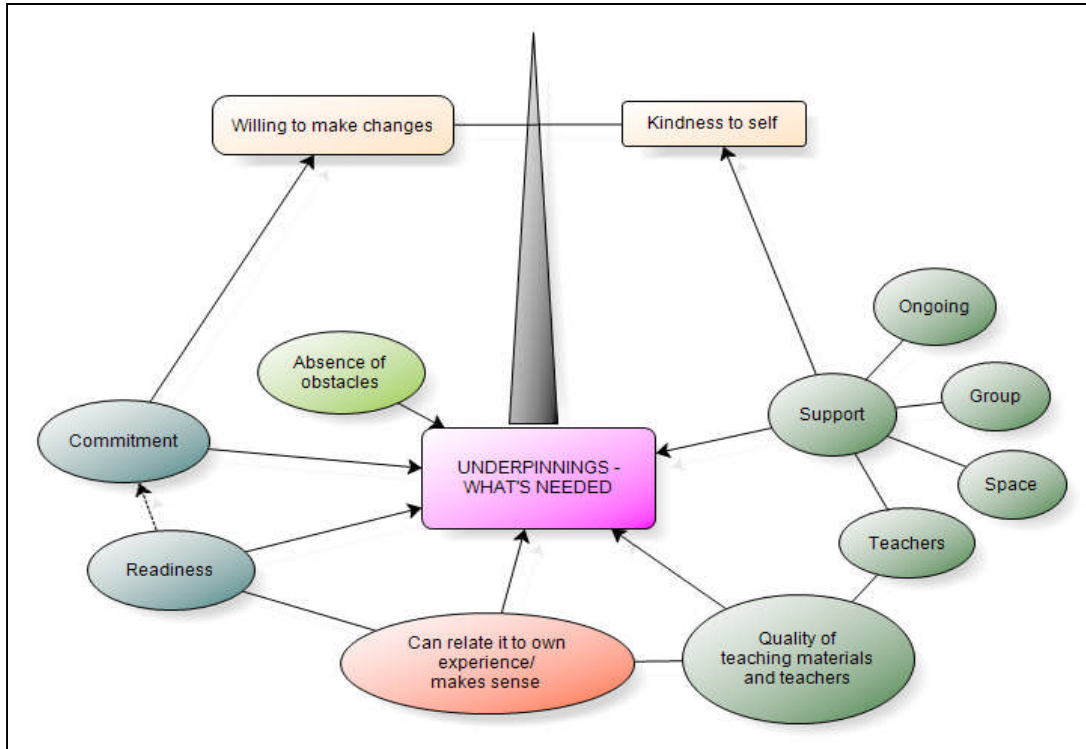
Part 3: Outcomes

Part 2: Process

Appendix J: Graduates' focus group confirmation details

Thank you so much for agreeing to participate in this focus group. I really appreciate you giving your time to come and contribute your thoughts and experience to this research. This information is to give you final details of the group, and some background information about what we will be discussing.

PRACTICAL INFORMATION

Time
We will meet at 1:30 pm on Thursday, 5 July and will finish by 3:30 pm. There will be time at the beginning to get a drink and complete any necessary paperwork, and I hope we can start the actual discussion at about 1:45 pm.

The discussion will last about an hour and a half, and we will decide at the beginning whether people would like to take a break part way through or would prefer to finish slightly earlier.

Location
The meeting will be held in the library at Manchester Buddhist Centre,   This room is on the top floor of the building, but there is a lift from the ground floor. In order to get into the Centre from the street, there are 6 steps. Staff are happy to assist people with the steps, but there is no other access to the building – if this will cause a problem, please contact me.

The Centre is close to the tram network and car parks, and there are disabled parking spaces nearby. For full travel details, the best thing would be to look at the Buddhist Centre website, which is at www.manchesterbuddhistcentre.org.uk then click on **Info** on the top right , and select **Contact/Find Us**. Alternatively, you can contact the centre by phone on 0161 834 9232 to get detailed information, and staff will be able to advise about specific queries.

Refreshments
Tea, coffee and herbal teas and cake or biscuits will be provided. If you wish to have lunch before the meeting, there are a number of cafes nearby including one in the basement of the Buddhist Centre itself. This is accessible by lift from the main reception of the Buddhist centre

Reimbursement of expenses
You will be able to claim your travel expenses for attending the meeting, either for public transport or, if you need to drive, for petrol costs. Expenses claim forms will be available at the meeting – please note that you will need to provide receipts (except for petrol).

Paperwork
As this focus group is part of my research, there are a couple of forms that need to be completed. I am enclosing them with this mailing, and if you have a chance to look at them and complete them beforehand that would be helpful, but don't worry if you can't or would prefer not to. There is no need to post the forms back beforehand – just bring them with you and I will collect them in at the beginning. If there is anything that you don't feel happy about or want more information about before you complete the form, there will be time at the beginning of the meeting to discuss this.

The two forms are:
Consent Form
This helps to make sure that you understand exactly what is involved in the research, and what will happen to the information that you share in the focus group. There are a series of boxes on the form, and you need to INITIAL each one to show that you are happy with that point.

Participant Information
This helps to give background information about the participants in the research, and is important when writing it up, as it helps to show the range of people who have been involved. No individual information will be used which might identify you in any way.

ABOUT THE MEETING

What will happen?
A focus group is very much a discussion between the participants, where people share their experiences and perspectives on a particular topic, in this case mindfulness meditation and how it affects living with long term health conditions. There will be a number of specific questions to discuss, and the aim is not to reach agreement but to hear all the different points of view, so everybody's contribution is important. You will not be asked to share any specific personal information about your health, and all information that is shared will be anonymised so that you cannot be identified.

What will we talk about?
There will be a number of topics for discussion, and we may also talk about other things that come up during the meeting if they are relevant to the research. Some of the topics I'm planning that we will look at are:
- How, if at all, has mindfulness meditation affected your experience of living with your health condition, and in what ways?
- How, if at all, you use mindfulness and mindfulness meditation – in what situations, in what ways?
- How, if it has, your use of mindfulness and mindfulness meditation has changed over time, in what ways and for what reasons?
- Why is it that some people seem to benefit more than others from mindfulness meditation and what affects this?

I hope this information is helpful and I'm really looking forward to the meeting and hearing what everyone has to say. If you have any questions, please feel free to contact me, either by e-mail at hcjal@leeds.ac.uk, or phone on 0113 343 7175 or 07801 428322 (the mobile is more reliable as I am not at the University very often and it may be some days before I pick up a message).

[NB A similar sheet (not included) was produced for the trainers' focus group]

Appendix K: Graduates' focus group question schedule

1. Introduction (15-20 minutes)
Ground rules:
Contributing
- No wrong or right answers to any questions, encourage different views but respect for each other – not aiming for consensus – you are allowed to disagree!
- Won't ask people to disclose any info about their conditions, you choose what you want to share.
- Want to make sure everyone has a chance to contribute, as you've all made an effort to come – might mean I stop some people, specifically ask others.
Confidentiality
- Session being recorded but names will be changed, any identifying details removed to protect confidentiality.
- Afterwards, just remember that similarly if you do talk about this meeting, don't do it in a way that would identify any individuals.
Practicalities
– Toilets, drinks, help yourself to biscuits, water.
- Aware there are people with different levels of pain and energy – want to make session work as well as possible for you. Decision re break – discussion will last about 1.5hrs, can have a break in the middle or carry on and stop earlier? Go with majority.
If anyone needs to take a bit of time out, feel free to go downstairs and get a drink and come back.
Introductions
To me and the research – How does MM affect people's experiences of living with LTC?
- final year, end of data collection, already done interviews, building on this
- not part of Breathworks myself, not done the course
To Ana – role to support me, gather additional information in case recording fails etc
Intro to the group – mention common experience of Breathworks, but in different places.
Icebreakers
a) Individually - name, three words to describe how your day has been so far
b) Group – quick show of hands:
- who's been here before?
- who knows anyone else in the room?
- done course in last year, 2 years, etc
Developing a common understanding of MM – start with a provisional definition and get general agreement – see other sheet. Read out/put on flipchart.

2. Exploring people's experience of MM (15mins = 35mins)
First thoughts - what – if anything - has MM changed about your experience of living with your condition?
Prompts
- Has it changed how you look at yourself and your illness?
- How you relate to others in connection with your illness?
- In what ways?
- Are there particular things about your experience it doesn't help with and you hoped it would?

3. Using mindfulness – what do you do? How do you use it? (25mins = 60mins)
'Feeling equipped to cope' is the way I've described what a lot of people say about how they feel – having tools to manage what's happening in life. Does this idea make sense?

Want to look at <u>what</u> you use and <u>how</u> and <u>when</u> you use it.
How do you use mindfulness in your everyday life, and particularly in relation to your health and wellbeing? What do you actually do?
<u>Prompts</u>
- Which tools/ideas?   What situations?   What difference do you notice?
- How do you decide what to use? Do you use different things to help in different ways e.g. one thing to calm down, another to get energy
- How does what's happening with your illness affect how you practice, what you do? More/less/ different?
- Have you adapted things from how you were taught them?
- Has what you do changed over time? In what ways? What reasons?
- Anything that isn't helpful, or positively unhelpful?

Interested particularly in the relationship between formal MM and informal mindfulness practice and what each of these contribute (if they do) – people have told me various things – what's your experience?
<u>Prompts</u>
- Do you find both helpful?
- In what ways? What does each contribute?
- What specific role does the meditation itself have in your experience? Would it be enough on its own?

4.   How does it help? What actually happens? How does it change things? (15-20mins = 1hr 15/20)

A lot of people talked about acceptance. There are mixed feelings about it, but it seems to be an important part of the experience of MM in relation to LTCs. What do you think about the idea of acceptance? What does it mean to you? Is it helpful/unhelpful? Why?
Another thing that seems to be an important part of using MM is to be able to look at both your suffering/pain/problems and the good things that are happening at the same time – not trying to push one or the other out. Would you say that was true for you? Any thoughts on this idea?
People have talked a lot about both gaining control and letting go – these things seem like opposites but both seem to be true and important to people – what do you think about this? How does this work?

5.   Who benefits?   (10mins = 1hr30)

Not everyone seems to get the same amount out of MM, and Breathworks in general. People have talked about different things that affected this – being desperate, having tried everything else, having good support, being too ill, etc. Some people have particularly mentioned being 'ready' to benefit or not.
- What made it possible for <u>you</u> to benefit, or stopped you from doing so?

6.   Ending

Thanks for coming
Any questions?
When research will end – will send summary if you want – sign on list (email only)
Welcome to stay for a bit longer, have a drink – room available for a while
Remember to hand in claim forms or send to me

Appendix L: Trainers' focus group question schedule

1.   Introduction (10 minutes)
Ground rules:
Contributing
- No wrong or right answers to any questions, encourage different views but respect for each other – not aiming for consensus – you are allowed to disagree!
- Won't ask people to disclose any info about their conditions or self, you choose what you want to share.
- Want to make sure everyone has a chance to contribute, as you've all made an effort to come – might mean I stop some people, specifically ask others.
- With all these questions people are coming with 2 hats – own experience and experience of observing others. Feel free to share both.
Confidentiality
- Session being recorded but names will be changed, any identifying details removed to protect confidentiality.
- Afterwards, just remember that similarly if you do talk about this meeting, don't do it in a way that would identify any individuals.
Practicalities
– Toilets, drinks, help yourself to biscuits, water.
- Aware there are people with different levels of pain and energy – want to make session work as well as possible for you. If anyone needs to take a bit of time out, feel free to go downstairs and get a drink and come back. Move around if need to.
Introductions
To me and the research – How does MM affect people's experiences of living with LTC?
- final year, end of data collection, already done interviews, building on this
- not done the course though know a fair amount about it new
To Ana – role to support me, gather additional information in case recording fails etc
Intro to the group – do you all know each other?
- Name, first contact with Breathworks, how long as a trainer

2.   Who benefits? (20 mins = 30mins)
Some people's lives are totally changed by their experience of MM, others it seems less profound, others it doesn't seem to affect at all.   Some change whole outlook, others change some behaviours.   What affects whether/degree/depth of change?
Prompts
- Who benefits?
- Who doesn't?
- What factors affect?
- Does this relate in any way to how much people's lives have been changed by illness? How long they've had the condition? What they've tried? How desperate they are?
- Readiness - what makes someone ready to benefit from MM?

Mental or physical health problems – any difference between experiences on course?
- mental health: relevance of concepts: moving towards, acceptance, primary & secondary suffering, you are not your thoughts?
Relevance of mindfulness meditation to all conditions?
Prompts
- Is making a quiet enough mental space for meditation a particular challenge with some kinds of mental/emotional distress? Is mindfulness meditation most suitable or would something more structured work better? How to respond?

- Are there some levels of suffering that you just can't move towards? What affects this? If there are (or if someone feels this), how do you work with someone in that position?

3.   Using the tools, taking it on (20mins = 50 mins)
- Levels of adoption of mindfulness – some take on theory, some only practice – does this affect what happens to them afterwards? Do you need to understand or is doing enough?
- Patterns of practice – some develop regular practice, others use much more 'on demand', responding to situations, maybe many times during the day – does this make a difference to experience?
- A lot of people say they can only meditate if they use the CDs – they clearly are a really useful resource. Is this a different experience from someone who meditates without?

People often identify two kinds of mindfulness practice – formal i.e. meditation and informal i.e. mindfulness of everyday life. Want to look at relationship between them.
- What contribution does each make? How do they work together?
- Is meditation necessary or is informal practice 'enough'?
- Is this even a helpful distinction?

Can you separate out the impact of MM from the whole Breathworks experience? What do you think is its particular contribution, if it's possible to say?

4.   Breathworks context (10mins = 1hour)
What do you think is distinctive about the way in which Breathworks teaches MM? What do you think that brings?
How important is the idea of kindness to the practice of MM? How does it relate to MM? Is it part of mindfulness? Does it enhance mindfulness?

5.   Concluding question (15mins = 1hr 15mins)
What do you think are the biggest differences that MM makes to people's experience of living with LTCs?

Appendix M: Mind map of first interview data

This shows an example of the mind maps produced to summarise individual first interview data. Some details have been removed to ensure anonymity.