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Reflecting theologically on the impact of HIV in
Edinburgh with particular reference to infected
people, health and social care professionals, Scottish
churches and local agency, Waverley Care.

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Theology and Religious Studies

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Abstract

This thesis discusses the impact of HIV in Edinburgh on infected individuals, professionals and the Scottish churches. It is grounded in contextual practical theology, offering reflexive responses to evidence gleaned from oral histories. The thesis documents the development of a local agency, Waverley Care, exploring the influences and pressures that contributed to its distinctive ethos. The author was employed as chaplain to people living with HIV from 2000 - 2016; the pastoral and professional relationships that emerged from that ministry form the foundation for the research. Unstructured interviews were conducted and Interpretative Phenomenological Analysis was used to analyse, interpret and reflect on the resultant material. Personal stories and perspectives were shared, both by people living with HIV and by professionals in the field. The impact of living with HIV is shown by discussing issues such as the ongoing impact of HIV-related stigma and the challenges associated with living long-term with the condition. Attention is paid to the challenges arising as a result of multiple bereavements and the resultant spiritual questions that emerge. The impact on physicians is also evidenced, in particular the transition from treating patients before the advent of effective medication, to the situation in 2016 when HIV has been re-classified as a chronic illness. Recommendations on areas of ongoing concern are made for decision makers in public health, the churches and Waverley Care. Deep reflective analysis is offered, using the Stations of the Cross and models from bereavement work to provide frameworks for understanding. The contribution of the Scottish churches to the establishment of support services is recognised; the churches' influence, both positive and negative on discourse on human sexuality is discussed. The research evidences the impact of the provision of spiritual care within a secular agency, showing that it is possible to create sacred space and to deliver a sacramental ministry within a non-church setting.

Keywords: HIV; Edinburgh; contextual theology; reflexivity; oral history; phenomenology; chaplaincy; harm reduction; stigma; bereavement; spirituality; Waverley Care

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Author's declaration

I declare that this thesis is my own work
and that the work has not been submitted for the award of a higher degree elsewhere

Introduction

This study seeks to investigate the impact of HIV in Edinburgh, including its effects on those directly affected by the virus, and on the practitioners, such as health and social care personnel, involved in mitigating its impact and in supporting those most affected. The thesis documents the history of the city's response to the disease and identifies some of the ways in which people, organisations, churches and professional practice responded to HIV. I will argue that HIV has been an agent for change. What precisely this involves, and the positive and negative ways in which HIV has had an impact will be explored throughout the thesis.

This thesis covers a time span from 1984 to 2016, from the time of the earliest diagnoses in the city to the time of writing. There was a conflation of circumstances in the early 1980s which resulted in Edinburgh having a different infected demographic from other parts of the world. This epidemic was amongst injecting drug users and led to a radical response from those concerned with public health. The impact of these circumstances on those tasked with caring for infected people will be explored. The churches were significant stakeholders in the formation of support services in the earliest days, and their influence, which was both positive and negative, will be examined.

0.1 Locus as a researcher

This thesis emerges from my ministry as chaplain to people living with HIV. I was employed for sixteen years by Waverley Care, Scotland's leading HIV agency. My research is grounded within the personal relationships I developed, ensuring a level of trust and sharing that gives depth to the material. There is no other research based in Edinburgh that uses this approach. One example of HIV research that emerged from personal engagement and that addresses questions relating to drug use and HIV is Elizabeth Pisani's *The wisdom of whores. Bureaucrats, brothels and the business of AIDS* (Pisani, 2008). Pisani is an epidemiologist who began work with UNAIDS in 1996.¹ In this book she focusses on Indonesia where she worked on HIV research and prevention. She uses narrative as a device to explore the issues in the South Asian countries where she was based. Pisani's work recognises the attraction inherent in drug use and the consequential increase in HIV related risk. She notes:

[A]ll drugs make you temporarily stupid. Many drugs make you horny, or lazy, or careless, or all of the above. And all of those things make you more likely to have sex, or less likely to do sensible things like use condoms when you do, or both (Pisani, 2008: 76).

¹ UNAIDS was set up as a joint United Nations programme to address the global issues associated with HIV.

Pisani is a research scientist who uses personal stories to illuminate her findings. Reading her work, I am helped to understand the context by those stories and am encouraged to use a similar device in my work. My work is very different from Pisani's in that it is based in one city and grounded within a range of communities. It complements her work as it also seeks to use knowledge gained through observation and personal relationships to inform the research.

Pisani worked in areas where injecting drug use was common and she gained an understanding of the challenges facing public health decision makers. She is a strong supporter of needle exchange which, she suggests, happens 'quietly' in many parts of the world (Pisani, 2008: 249). The findings of her research support the early response in Edinburgh where policy makers reacted quickly and courageously to the knowledge that HIV had affected a significant number of drug users by introducing substitute prescribing and needle exchange programmes. I will explore the thinking behind those policies in chapter two (2.1.2) where I will show that the initiative was not universally welcomed but was, in fact, highly effective.

0.2 Design of this thesis

The research material comprises the personal stories and memories of people living with HIV and of professionals working in the field. The subjects of the research are restricted to those whose involvement or diagnosis encompasses the time before effective treatments became available in 1998. This allows me to reflect upon the impact of HIV both pre and post the introduction of treatment. I will show that although the prognosis for people living with HIV has improved beyond any recognition, there are still significant issues to be dealt with on a daily basis. HIV-related stigma continues to be a reality for many people and the impact of living long-term with the virus cannot be underestimated.

Oral histories were collected in 2015 and early 2016 and they, along with a small number of transcripts from interviews undertaken in 2012 and two case studies, inform the findings. The oral narratives were gathered in recorded one-to-one interviews with selected respondents. The decision making process relating to whom to interview is explored at 1.5.1. Throughout the study there are personal observations, reflections and analysis, especially in relation to the aspects of the research that concern practical theology and spirituality.

Chapter one defines the parameters for the research. It begins by clarifying my position as both researcher and chaplain, by recognising that I bring a personal and particular lens to this study. Reference is made to international writing on HIV and theology, while discussing the reasons why that work plays only a

limited role in this thesis. The chapter then focusses on the frameworks within which my research has been conducted.

I discuss practical theology and its relevance to my work, with particular reference to contextual practical theology. In the section on historical context, I make clear that the Edinburgh HIV epidemic manifested differently from the way HIV manifested in other parts of the world, requiring a quite distinct set of public health responses; this context is crucial to the content of the thesis. The importance of context is stressed by African theologian, Julian Müller, in his paper 'HIV/AIDS, narrative practical theology and postfoundationalism: the emergence of a new story' where he writes:

Practical theology is only possible as contextual practical theology. [...] I am not writing a practical theology *with reference to* HIV/AIDS, but a practical theology *developed out of* HIV/AIDS. It is the particularity of a practical theology that gives it life. (Müller, 2004: 296) (my italics).

This thinking gives me confidence in my finding that HIV in Edinburgh, and therefore the theology of HIV in Edinburgh, is distinctive. The stories I will share and the theology I will explore are unique to this place and time.

Chapter one continues by outlining and defending the value of reflexive practice. I describe the value of reflexivity and its importance as a safeguard against the abuse of trust or power in the research process.

Chapter one proceeds to elaborate the research methodology. I have used oral history as a tool to gather the narratives that form the core of the research material, and I have employed hermeneutical techniques of textual interpretation to analyse this material. My chosen methodology falls within the field of phenomenology and I describe the origins of this research method. The branch of phenomenology that I am using is Interpretative Phenomenological Analysis and its origins and methods are described.

The chapter continues by referencing and offering comment upon core sources of historical information on the history of HIV in Edinburgh. I then explore the ethical issues pertinent to this research. Finally, there is a section which explores the nature of my role as an employee of Waverley Care and discusses the various responsibilities and multiple aspects of that role within the organisation.

Chapter two focusses on the history of HIV in Edinburgh. It charts the history of heroin use in the city and the decisions made by those who sought to manage the problem. It makes clear that the emergence of a significant epidemic amongst injecting drug users in the city had an impact on the responses from

health, social care, the voluntary sector and the churches. I will show that there was a real fear that there would be onward (sexual) transmission into the wider population and that those fears were a driver for many of the public health decisions that were made. I draw on historic records which are augmented by extracts from the oral histories to evidence the importance of this particular epidemic for the development of harm reduction strategies, including the introduction of substitute methadone prescribing, the availability of clean injecting equipment and free access to condoms. Attention is paid to the decisions made by those who sought to reduce onward transmission and to the impact of those decisions on healthcare services.

The chapter compares the experiences of clinicians working in the two centres in the city that specialised in supporting patients who were diagnosed with HIV. One clinic was mainly concerned with treating injecting drug users whilst the other saw the majority of gay men who were infected. In both cases, they were often seeing patients who had other problems and whose attendance could be erratic. The public health imperative associated with this virus put pressure on the clinics to make it easy for those patients to attend and there are descriptions of the impact of HIV on the management of clinics.

The responses from within the community are described, and the contribution of the churches is assessed. The impact of the churches was, in many ways, positive and their involvement ensured that appropriate services were offered quickly. However, the influence and attitudes of the churches were not always positive and the impact of church-based negativity is explored. Finally, the creation of Waverley Care, including the opening of Milestone, a purpose-built hospice, is described.

Chapter three shares research material pertaining to the situation before 1998, that is before effective treatment was available. Clinicians and people living with HIV describe the process and impact of diagnosis and the resultant emotional responses. This work is distinctive in its use of personal narrative from clinicians. They are sharing their memories of a time and situation that had a significant impact on them and on their city. The service users who participated in this research speak freely of their experiences and the impact on them of HIV. Stigma is a theme that recurs throughout the narratives and which continues to play an important part in the lives of people who are living with HIV. The chapter explores stigma from a number of perspectives including the impact on families, the experience in medical settings and stigma in the public arena.

Chapter three then investigates the changes that people chose to make as a result of their diagnosis, and gathers reflections from those infected with the

virus on the impact of HIV on their lives. We discover that there were positive and negative outcomes for people. For instance, some decided to stop using drugs and to focus on improving their health, while others felt that they had to impose limitations on their engagement with other people. An HIV diagnosis has an impact on the individual's sense of their own mortality and, sometimes, on their engagement with a faith community. People made plans for their own death and they dealt with a number of bereavements. Those themes are discussed in depth within this chapter.

Chapter four is concerned with the reflections of people who have lived through the introduction of treatment in 1998 and who are now finding ways to live with their HIV rather than preparing to die from AIDS. It considers the availability of treatment on clinical practice and evidences ways in which the medical professionals are able to function as doctors who offer healing and hope. It discusses the creation of community amongst people living with HIV and the importance of peer-support. I suggest that the community that was created at Waverley Care Milestone was church-like in its engagement with people and I describe how a Christian ministry was exercised within a secular environment.

HIV had a significant impact on personal relationships for the participants in this project and that theme is explored. A number of respondents identified their personal determination as a factor in their survival; those narratives are shared. The chapter then moves on to discuss the impact of HIV on health and social care professionals. It looks at the ethos of Waverley Care and the influence of that agency on its staff and their families. Finally, in this chapter, I consider the influence of Christian principles on HIV care and support.

Chapter five is comprised of theological reflection on the findings of the research. It is written from a personal perspective and includes much of my reflexive engagement with the material. I use a number of the Stations of the Cross as a lens through which to reflect on key themes such as condemnation, stigma, Christian care and support, and mortality. I share the impact on my own spiritual journey.

The chapter moves on to discuss funerals and the learning there is from HIV about making all funerals accessible, regardless of the belief system of those involved. I suggest that the ministry at Waverley Care was an example of mission and use the example of a community choir to illustrate the point. I explore the priestly nature of the ministry and the creative ways that it was possible to express faith outwith a faith community setting. I focus on religious ideals of faith and hope and their relevance to this community.

The chapter then moves on to frame the findings within a research model. I discuss John Bowlby's attachment theory and then use two models from bereavement theory to fully understand the processes that people have experienced. I use one of those models to reflect upon my own experience of redundancy and its impact. Finally, I draw conclusions and make recommendations for further research projects.

0.3 Aims of the research

My work has a number of aims and objectives:

To ensure that the particular context for HIV in Edinburgh has been captured correctly, adequately described and thoroughly examined. I achieve this by sharing historical information emerging from documentation, written material and oral history. I have ensured that work is firmly grounded within the field of practical theology.

To ensure that the history and impact of HIV in Edinburgh is told through the voices of and from the perspectives of those most affected by the disease, especially those who were diagnosed as HIV positive when no treatments were available. I aim to 'give a voice to the voiceless', to recognise that the subjects of this research are the experts in their own stories and their own histories. I allow the participants to define the territory and to share the areas of life and experience that are most important for them. At first sight, the professionals who have made a significant contribution to my research may not be perceived as voiceless. Many have published on the subject, in each case documenting factual information, often from a clinical perspective. This study is different. It allows them to share their personal stories and to reflect on the impact on their clinical practice and on the relationships they have built with their patients and service users.

To identify the responses to HIV from within the medical profession, including the introduction of harm-reduction initiatives. I explore the rationale for the introduction of substitute opiate prescribing and needle exchange, and the range of attitudes to those measures that were prevalent in the 1980s and early 1990s.

To explore the impact of HIV on medical professionals and the management of their clinics. I compare and contrast the experience of the clinicians who were based within a sexual health context with that of those who were in infectious diseases.

To consider the impact of the Scottish churches on support services for people who were living with HIV. I address issues relating to attitudes emanating from some of those churches which were not always in harmony with the activities

they were engaged in. I suggest that HIV has influenced church thinking about human sexuality and has contributed to a shift in attitudes.

To describe the creation of Waverley Care and, in particular its dedicated HIV hospice, Milestone House. I will show that the ethos of Milestone was significant in the lives of both service users and staff and that they were influenced by their engagement with that service.

To explore the impact of stigma on the lives of the participants. I will show that stigma affects both people living with HIV and their families, and those who seek to support them in both health and social care settings.

To consider the impact of HIV as an agent for change in the lives of people both infected and affected. I will show that living with HIV has encouraged a re-evaluation of lifestyle and attitudes.

To explore the impact of living with a life-limiting condition on younger people and its effect on their attitudes to mortality. I will show that HIV has forced a generation of people to deal with death and dying and to consider their wishes for the end of their own lives.

To use two models from bereavement theory in order to provide a framework for further reflection and analysis. I will compare the two models and share my reasons for preferring one over the other. I will use that preferred model to reflect on my own circumstances.

To reflect theologically on the impact of HIV in Edinburgh using some of the Stations of the Cross as a means through which to engage with the issues. I will share the impact of working with HIV on my own spiritual journey.

To produce recommendations, in light of this research, that could (i) inform the future of chaplaincy services to those affected by HIV in Edinburgh; (ii) encourage churches and other faith communities to find opportunities to welcome people who are living with HIV and to play their part in education, thus reducing onward transmission; (iii) identify further follow-up research to monitor and map the future likely impacts of HIV.

Chapter 1: Approaching the research project

1.1 The context

I am a priest within the Scottish Episcopal Church. In the year 2000 I was hired by an Edinburgh-based voluntary sector agency, Waverley Care, as their chaplain. Waverley Care supports people who are living with HIV and/or Hepatitis C.² I was employed by Waverley Care for sixteen years until, in 2016, a decision was made that a dedicated spiritual care role would no longer be a part of the agency's staffing complement.

As a priest working in this environment, I am in a privileged position. I have an active Christian ministry, authorised by my bishop, to which I bring an unusual skills mix for someone in ordained ministry. Alongside my theological training and ministerial formation, I have a background in community-based social care with some of the most marginalised people within our communities. The client groups I have experience of include homeless people, substance abusers, street prostitutes and young women who have experienced sexual abuse. This body of experience and the associated training that I have undertaken give me a knowledge base and grounding in a broad range of issues which, in turn, allows me to work in a deep and holistic way with the service users that I encounter. That depth of engagement enhances the material I have gathered and ensures that the stories I am able to share are rich and deeply personal.

1.2 Historical background

Edinburgh has a particular history of HIV that is important to document, both for me as a theologian who was working in the field, and from the perspective of social history. A new approach was taken to drug users in the city in the early 1980s, at the same time as (unbeknownst to the decision makers) HIV was being introduced into the city, probably by someone who was visiting from the United States. The Edinburgh HIV story emerges from the convergence of a particular set of circumstances at a particular time; that history will be explored and documented fully in chapter two.

² There is an Edinburgh Hepatitis C story to be told, but it is not the subject of this thesis which concerns itself solely with HIV.

Previous studies, for example unpublished theses by Helen Coyle and Neil Olley and the published MD thesis by Dr. Ray Brettle, address the story of HIV in Edinburgh and some of the attendant issues, such as historic drug policy. Their research data is mostly derived from written material, minutes of meetings, reports of committees and the recommendations of working parties. These are important pieces of work that have informed my own study and acted as reference (and cross-reference) material. However, the people who have lived through the thirty-three years since HIV was first recognised in Edinburgh have their own histories and stories to tell. Their memories of actual events may not be perfect, but each one is able to speak about their personal journey and the impact of living, and in some cases working, through this time of change and development.

1.3 HIV and theology

HIV and theology is an area that has attracted scholarly interest, almost always with reference to high prevalence countries. The large Christian charities, such as Christian Aid and Tearfund, have produced materials on HIV, all of which have a focus on countries where heterosexual communities are most affected. There is a substantial body of work addressing theological issues with respect to HIV in Africa. For example, the 'Collaborative for HIV and AIDS, Religion and Theology' (CHART) at the University of Kwazulu-Natal hosts an extensive database of material (CHART, 2008). I have not cited such material as it has no direct relevance to the contextual research I have undertaken.

Other authors have explored HIV and theology from a different perspective. In his book *Breaking the Conspiracy of Silence: Christian Churches and the Global AIDS Crisis*, Donald Messer recalls attending an ecumenical conference on HIV in Mumbai. The central logo was a cross wrapped in a red ribbon (to symbolise AIDS). The 'tag line' alongside the image was 'the body of Christ has AIDS' (Messer, 2004:19). The phrase 'the body of Christ has AIDS' has become well used within the churches; the Methodist church produced a poster in 2004 using that message. It is not a concept which I find appropriate in my context. It seems to fit well within, for example, an African context where everyone within a community has had some contact, either directly or indirectly, with HIV. In Edinburgh however, HIV has always been confined to particular parts of the city

and to marginalised groups of people (gay men, drug users, sub-Saharan Africans³ and haemophiliacs). For a church to declare that the body of Christ has AIDS, that church would need to be directly affected by the virus, to have some real, lived understanding of its impact. This is the difference between sympathy and empathy. Church members in Edinburgh are, to a large extent, sympathetic to the plight of people living with HIV in their communities. However, I know from the experience of speaking about HIV in church contexts that the majority of the people in those congregations are ill-informed about HIV and do not think that they have ever met someone who is directly affected. For our churches to express empathy, there would need to be some deeper understanding of what it might mean to live with HIV, some understanding of the challenges that people face. I hope that this thesis will offer insights to educate people in those ways.

1.4 Practical Theology

This research has been undertaken within the parameters of study for a professional doctorate in practical theology. I write as someone who is an ordained priest with a commitment to theological reflection. The discipline of practical theology allows me to bring my professional practice and my theological reflection together and to explore the learning within each discipline which is applicable to the other.

Practical theology has been described by Bonnie J. Miller-McLemore in *The Wiley-Blackwell Companion to Practical Theology* as:

[A]n *activity* of believers seeking to sustain a life of reflective faith in the everyday, a *method* or way of understanding or analysing theology in practice used by religious leaders and by teachers and students across the theological curriculum, a *curricular area* in theological education focused on ministerial practice and subspecialties, and, finally an *academic discipline* pursued by a smaller subset of scholars to support and sustain these first three enterprises (Miller-McLemore, 2012:5) (her emphasis).

My endeavours, as a researcher in this instance, fall primarily into the latter of the descriptors, that is an academic discipline. I am seeking to share the

³ There is a very small population of Africans living in Edinburgh. Glasgow is a dispersal centre for asylum seekers and therefore has a larger population.

knowledge I have gained both within my ministry and as a result of my research, in order to inform and resource people within the faith communities and beyond. My belief is that the learning and challenge that arise from my research are relevant to people of all faiths and to those who are on a journey of exploration. The personal endeavour that has contributed to the research falls into the first of Miller-McLemore's definitions (activity), an engagement with reflective faith which has ensured that I have kept a focus on the Divine throughout my ministry.

The lived practice of the practical theologian is described by Laurie Green in his book *Let's do theology* (Green, 1990). Green explores the movement from practice to reflection and back to practice as a tool for growth and development, describing this as a hermeneutic circle. Hermeneutics, or textual interpretation, is a core tool for the theologian combining as it does attention to scripture with a prayerful approach to action and decision-making. This approach, which directly incorporates reflection and evaluation, links with work in the field of psychotherapy which was undertaken by James Prochaska and Carlo di Clemente when they were looking at smoking cessation (Prochaska and di Clemente, 1982). The focus of their work is entirely different but they recognised the importance of allowing for reflection which enabled internal movement, leading, in turn, to behavioural change. Green uses the phrase 'transformative purpose' to define something similar, emphasising his understanding that theology must change lives, not just thinking (Green, 1990:106). I am able to conclude from interviews undertaken under the umbrella of this research project that the theology I was able to undertake did, in fact, change lives. This will be evidenced in chapters three and four where the narratives I share give voice to people's experience of change. It was borne out in a very powerful way when I was leaving Waverley Care and one of the service users told me that I brought hope into the lives of people living with HIV and into the agency.⁴

⁴ Personal conversation, March 2016

1.4.1 Material for reflection

At its heart, this research project has the people whose lives have been directly affected and changed by their contact with HIV. Their stories, told in their own voices and their own language, allow the reader to engage with the full history of HIV in Edinburgh. Their stories are powerful and compelling. My hope is that they will encourage the reader into their own reflections; that these stories of change will in turn change those who learn about them through these pages

The core source of material for the theologian is, of course, scripture. However, it has never been the sole source of written material within religious groups. For instance, the writings of mystics have had an important place within the Christian community, as have works of religious art such as icons. In the early twentieth century attention was paid to another core source, the lived experience of women and men as observed and reported to researchers. Miller-McLemore describes this important shift:

[E]arly twentieth-century psychology demonstrated the value of the close study of the 'living human document' as a valid 'text' for theological study, comparable to traditional texts of scripture and doctrine (Miller-McLemore, 2012:1).

The transcribed words of the subjects of my research, the documented stories of the individuals who have lived these experiences, become the text which will form the focus for study and theological reflection. This is an opportunity to use material that has been shared by people who trust me to honour their stories and to understand their perspectives. The people who have entrusted me with their life stories have become the living human documents, the text to be studied. The phrase 'living human documents' was first used by Anton Boisen in his work on mental health and religious experience (Boisen, 1960:185). He built up a model for professional development that was based on shared case studies, using the living human documents that were brought into reflective practice groups by professionals as the core material for sharing experiences and learning.

1.4.2 Reflexivity in the research process

The theological reflection which will inform much of my writing will feed into a reflexive process. Heather Walton in *Writing Methods in Theological Reflection* makes a clear distinction between reflection and reflexivity:

The terms ‘reflective’ and ‘reflexive’ are overlapping and sometimes used interchangeably. However, strictly speaking, reflective processes are characterised by acute observation of roles and context. Reflexivity takes this critical work a step further and also interrogates the position of the ‘self’ who observes (Walton, 2014: xii).

The bias and influence of the self who observes must be taken seriously in this research project. I interviewed and observed and reflected from within an organisation and from a position of trust. That privileged position gives me both an advantage and an additional responsibility as a researcher. I have inside knowledge both of HIV and of the lived experiences of my participants and therefore I was able to gather deeper and more pertinent material. I had to take care not to exploit the participants or to transcribe material that was not appropriate for sharing. My own personal story has been affected by HIV as a result of working in the field for thirty years and I have chosen what to share from that. I am not able to separate entirely my own memories of how things were in the early days of HIV from those that have been shared by my research participants. I have taken care to set aside, in so far as I am able, my own interpretation of times and events and to allow the stories, as shared with me, to be told with integrity. I have then returned to those stories and allowed myself to reflect and then to write reflexively on them. In chapter five I have brought together my own spiritual journey and my additional reflections on the research.

1.5 Research methodology

1.5.1 The living human documents

When approaching the interview stage of my research, I was faced with decisions about who to interview and how to limit the scope of the material I might gather. Thinking about the people living with HIV, I decided only to interview people who were diagnosed before effective treatment was available; that is

people who were diagnosed before 1998. That group of people is of particular interest to me as they have lived with HIV for upwards of twenty years and are therefore able to share their stories of living and journeying with the HIV virus over a significant period of time. They were all diagnosed at a time when the prognosis was very poor; the expectation was that they would die within a few years. Their stories are therefore ones that take us from the despair of a terminal diagnosis to the hope that came with the advent of effective treatment. The service users I know who have been recently diagnosed (in the past five years) are almost all still adjusting to their diagnosis. It will become clear as we read the oral histories in chapter three that an HIV diagnosis brings with it a sense of loss which requires psychological and spiritual responses. People need time to adjust to their new reality. The people I interviewed for this dissertation have all engaged, at least to some extent, with that process. Newly diagnosed people have stories to tell, stories of receiving a twenty-first century diagnosis, but they do not fall within the parameters of this research project. This research concerns itself with those whose lives with HIV have taken them from a time when there was no treatment and no hope to a situation where their HIV is not normally the most important thing in their lives. I explore that personal journey and internal process within this thesis. For more recently diagnosed people, the process of adjustment and the impact of diagnosis are different. Treatment is available. Life expectancy is near normal. There is, for instance, no reason to consider stopping work, no bar on accessing life insurance, no reason to choose not to have children, no reason to assume that the future will be bleak and lonely. That is in direct contrast to the stories you will read in chapter three where people describe responding to their diagnosis in the early days.

The professionals who participated in this project are clinicians and colleagues who have all been involved in the field for at least twenty years, the same time period as the service users. The story of HIV in Edinburgh will therefore be shared from the perspective of both patient and clinician, service user and care giver, on the same historic axis. I use the methodology of oral history in order to gather the material which forms the heart of this research project. Oral history is distinctively associated with the telling of recent history. Its integrity is held both in the process of story telling and in the creation of written records

of those stories (Abrams, 2010:3). The oral histories I gathered from people who are living with HIV capture the story of people's journeys from despair to hope. The professionals also describe a journey from the despair they experienced in the early days when they had nothing to offer, to the hope they were able to offer with the advent of medication. There is discussion of the impact of a terminal diagnosis, the change that treatment brought, and the impact of living long-term with HIV on individuals and the significant people in their lives.

A distinctive feature of this work is that the stories that were shared with me were all told by people with whom I have an existing relationship. The service users are people whose lives I have supported and whose stories I already knew, at least in part. The professionals are colleagues, some known to me for thirty years, people with whom I have mutually respectful relationships. This has allowed a depth of conversation and sharing that is not always found in academic research. Researchers are often unknown to the participants of their study and may only have a partial understanding of the field. For many, the research is undertaken in order to broaden their understanding, for example, of how people cope day-to-day with their HIV. Those are not questions that I needed to ask, since I work alongside these people day-by-day and have a core understanding of the issues that they face. The impact of concentrating on existing relationships can be seen in the quality of the material that has been shared, by both service users and professionals. H. Lea Gaydos, exploring the value of personal narrative in nursing practice, suggests that memory actually helps to create meaning for the narrator. She says 'Personal narrative is a form of autobiographical storytelling that gives shape to life experience' (Gaydos, 2005:254). I am encouraged by this as it suggests that there was a direct value for participants in sharing their histories and processing those stories and events for themselves.

I interviewed seventeen people in the course of this research. Five of them are living with HIV; five are members of staff within Waverley Care; four are clinicians, two from each of the clinics in Edinburgh which care for people living with HIV; one is a long-term supporter of Waverley Care; and two were involved in the creation of the earliest support services in the city. I had intended to interview two additional service users. One died before she was able to record the interview and the other has been physically unwell for a number of months.

There is an interesting observation to be made here about the health of people who are living with HIV in Scotland at the time of writing (2016). Newly diagnosed people can expect to have a normal life expectancy; HIV is now perceived as a chronic condition that is not life threatening if the patient's health is stable on medication (NHS, 2015). However, the subjects of this research are people who have been diagnosed for many years and whose immune systems became compromised before 1998. Experience of supporting such people in recent years shows that their underlying health is not always good and that they continue to experience more physical problems than their HIV negative peers. There is also a significant cohort who experience cognitive impairment. One recent study suggests that 48 percent of people infected with HIV and taking treatment have measurable cognitive impairment (Harezlak et.al., 2011:625). This further limited the potential participants for this research as I was keen to interview people whose memories were still good.

1.5.2 The process of gathering data

My interviews were deliberately conducted in an open way. I invited people to tell me their story and follow up questions arose directly from their answers or from links that I was making with material that I had already gathered. I was most interested in hearing about the detail of what happened to people, looking for what Clifford Geertz, following Gilbert Ryle, describes as 'thick description' (Geertz, 1973:6). Geertz is writing here as an anthropologist and he makes it clear that the interesting task is to gather material in a holistic way:

In anthropology, or anyway social anthropology, what the practitioners do is ethnography. And it is in understanding what ethnography is, or more exactly what doing ethnography is, that a start can be made toward grasping what anthropological analysis amounts to as a form of knowledge. This, it must immediately be said, is not a matter of methods. From one point of view, that of the textbook, doing ethnography is establishing rapport, selecting informants, transcribing texts, taking genealogies, mapping fields, keeping a diary, and so on. But it is not these things, techniques and received procedures that define the enterprise. What defines it is the kind of intellectual effort it is: an elaborate venture in, to borrow a notion from Gilbert Ryle, 'thick description' (Geertz, 1973:6).

The interviews I conducted were underpinned by values I have learned within the world of counselling. The interviews were not counselling sessions, but I

took seriously my responsibility to put my training and experience into practice in order that the meetings were framed within professional guidelines. Carl Rogers' core values of Person Centred Counselling are empathy, unconditional personal regard and congruence (Mearns, Thorne and McLeod, 2013:125). These core conditions are perceived within the world of counselling, and beyond, to be the foundation upon which a client can feel valued and accepted by a listener. The first of those conditions, empathy, is about seeing a situation from the other person's perspective, to use a well-known phrase, walking a mile in their shoes. Its importance is felt strongly by people who are sharing difficult material; it is vital that they do not feel judged and that the listener is doing all they can to understand what happened to that person and how it felt for them when the events they are describing unfolded. The second core condition, unconditional positive regard, is experienced by the client as respect for them and their values. Nothing the client shares can be wrong; it is not the role of the listener to contradict but rather to recognise and respect that the person is telling the truth as they experience it. Congruence, the third core condition, requires the listener to be honest and real within the session. This may mean that they respond to something by, for example, sharing that they are feeling a deep sadness as they listen. The client is then assured that the listener is fully present and that they are engaged with the material they are hearing.

The importance of these values within the caring professions can be seen in the way they have been adopted in healthcare, social work and voluntary sector settings (Open University, 2013). It is of utmost importance to me that any contribution from a service user is treated with respect, is treated as fact, and does no harm to that individual.

Counselling training taught me to listen in a particular way. This is, active listening, paying attention to what is being said as well as what is left unsaid. It requires attention to body language, to the silences that may arise and to my personal responses that may not be directly related to the client or their presenting issues. By ensuring that the interviews were framed in this way, I was able to ensure that the participants, in particular the service users, the more vulnerable of the interviewees, were not becoming uncomfortable or distressed. There was one interview which began to distress the interviewee

and I stopped immediately. I offered the participant the option to finish there but she decided to re-engage and to finish telling her story.

1.5.3 Checks and balances in the research process

My research with individuals began with a conversation about the aims and parameters of my research and an invitation to participate. Each potential interviewee was given an information sharing document to read which made clear what the research aimed to achieve and how the resultant writing might be shared.⁵ Service users were asked to discuss their proposed participation with another member of staff in order to ensure that they fully understood the implications and that they were not being pressurised into participation. Consent forms were shared and signed. Arrangements were then made to conduct the interviews, which were all recorded and later transcribed. Those interviews were essentially unstructured. Each interviewee was asked an opening question, either ‘tell me about receiving your HIV diagnosis’ or ‘what brought you into this field?’ Subsequent questions were dependent on the answers given and the direction taken by the interviewee. As interviewer, I aimed to avoid undue influence and to allow the interview to be shaped and directed by the interviewee.

Participants were offered the option to waive their right to be named as the author of their material. Most of the people living with HIV chose to use a pseudonym. All professionals interviewed are named in full. Pseudonyms are written throughout in italics. I chose to ‘tidy up’ the transcripts I gathered, taking out the repetitions and hesitations but taking great care not to alter the sense of the material.

1.5.4 Frameworks for the research

Locating this research within a discipline and choosing a methodology have proved to be complex tasks. My discipline is practical theology and the learning from the research is offered in the form of theological reflection. Gathering the research in a structured and helpful way was a challenge that led me to explore

⁵ Detail, including ethical considerations, can be found at 1.8 and the documents form appendix 2.

other disciplines. The work aims to offer a social history of HIV in Edinburgh and to make some reflections upon that history, always remembering that my reflective and reflexive work is firmly grounded in theology. Raphael Samuel in his paper 'What is social history?' answers his question in this way:

[It] prides itself on being concerned with 'real life' rather than abstractions, with 'ordinary' people rather than privileged elites, with everyday things rather than sensational events (Samuel, 1985).

I was keen not simply to share people's stories, but also to explore the learning that has arisen from those stories and to make connections with stories that are at the heart of religious teaching. The oral histories have been allowed to speak for themselves and they form a rich and powerful narrative. The analysis has allowed me to make connections between those narratives and to draw out themes for further consideration.

Elizabeth Conde-Frazier writing in the *Wiley-Blackwell Companion to Practical Theology* addresses the value of oral history within practical theology. She notes that 'Oral histories are an especially good form of empowerment for persons who suffer oppression' and remarks that they 'carry the knowledge of the people' (Conde-Frazier, 2012:238).

The stories I will share are real life stories of ordinary people whose lives have been changed by an extraordinary convergence of events. The importance of these stories is emphasised by Conde-Frazier's description: these are the empowering stories of people who have suffered oppression and who are the only people with that lived knowledge. In chapter two I document the history of HIV in Edinburgh, a narrative that shows how easily two seemingly unrelated areas of life (in this case drug enforcement policy and the emergence of a new virus in the United States) impacted on the lives of a cohort of people, inflicting significant change. The social histories will enhance our understanding of the existing written history and the resulting knowledge will then allow us to have a more comprehensive understanding of the events that unfolded.

1.5.5 Phenomenology

Phenomenology is a methodology that has been used extensively in health and social care research. It is concerned with the meaning of lived experience for an

individual or group of individuals who have encountered an identified phenomenon. In his work, *A Phenomenology of Practice*, Max Van Manen suggests that it 'aims to grasp the exclusively singular aspects (identity/essence/otherness) of a phenomenon or event' (Van Manen, 2016: 27). It is a philosophical approach that seeks to name what the participants identify as the impact on them of the phenomenon and, where they emerge, to identify shared experiences within individual narratives. In *Qualitative Inquiry and Research Design*, John Creswell defines the end-point of a phenomenological analysis, 'The phenomenological report ends with the reader understanding better the **essential, invariant structure (or essence) of the experience**, recognising that a single unifying meaning of the experience exists' [his emphasis] (Creswell, 1998:55). Creswell and Van Manen are both suggesting that there are identifiable markers that allow us to confidently discuss that which those who experience any defined phenomenon have in common. This methodology allows a researcher who has not shared the particular experience herself, but rather has explored in depth the experiences of those whose stories she has heard, to better identify the distinguishing impact of a named phenomenon. It seeks to identify that which makes a particular experience *that* experience rather than something else. John Swinton and Harriet Mowat describe it as an approach that 'allow[s] the researcher access into the inner experiences of research subjects' (Swinton and Mowat, 2006:105).

Phenomenology is distinctive in its goal of understanding the impact of events, 'What is this or that kind of experience like?' (Van Manen, 1990:9). Central to the practice of phenomenology within the research environment is a commitment to understanding the phenomenon through the voices of the respondents. This is a methodology that comfortably embraces oral history, the tool used to gather the core data for this study. The decision I made to record unstructured interviews in order to gather the social histories of people I interviewed fits well within the parameters of phenomenological research which have been described by Stan Lester in his paper 'An introduction to phenomenological research' as:

[G]athering 'deep' information and perceptions through inductive qualitative methods such as interviews, discussions and participant observation, and representing it from the perspective of the research participant(s) (Lester, 1999:1).

Lester's view is that these approaches emphasise the importance of personal perspective and interpretation. The foundation of phenomenology is that the participant is the expert in their own life and that any interpretation by a researcher is valid only in so far as it observes that lived experience in a non-judgemental way. The salient point here is that the observations are made from a position that is as neutral as possible. It is not possible for an embedded researcher to work without any prejudice, but it is possible to have an acute awareness of the potential for imposing one's own life experience on the stories of others. I have mitigated against this danger by offering minimal comment in chapters three and four which form the core of the testimonial section of this thesis; rather, I have offered reflection and analysis within chapter five where I share my personal perspective and experience. John Creswell encourages such an approach when he writes: 'The researcher needs to decide how and in what way his or her personal experiences will be introduced into the study' (Creswell, 1998:55).

I consider that phenomenology offers a helpful framework and a good opportunity for deep understanding in my particular field of enquiry. The data I have gathered is immersed in personal experience of the phenomenon of HIV, a stigmatised and stigmatising condition. John Swinton and Harriet Mowat, in their analysis of the value of phenomenology within the context of a research project say:

Phenomenological insight, in providing deep insights and understandings into the way things are, enables people to see the world differently, and in seeing it differently to act differently towards it (Swinton and Mowat, 2006:107).

My hope is that this approach will contribute in some small part to a deeper and more tolerant understanding of what it is to live with HIV. In order to attain this goal, individual and collective stories have been shared and explored. My analysis has allowed me to make connections between those stories, to identify common strands, to recognise personal perception and to examine the wider impact of the HIV virus. My work does not follow phenomenology in a prescriptive way; I am not seeking to identify that which uniquely defines what it is to be living with or affected by HIV. Rather, I am using phenomenology as an approach, a broad frame within which it will be possible to share deep and intense oral histories and to allow the reader to engage with the narrative as told by those people who are directly affected.

Some scholars have cautioned against using a phenomenological approach to draw generalised conclusions. The small sample size of a typical study of this nature, and the fundamental understanding that this approach is primarily honouring individual perspectives and experiences, cannot be ignored. John Paley addresses this question in his paper 'Phenomenology as rhetoric' when he writes:

The study of 'lived experience is not an assessment of an objective reality but a description of the reality as it is articulated' by the respondent (Thomlinson, 2002:539). It is a question of 'perceptions' and 'meanings', not measurements and causes (Paley, 2005: 107).

My work gives a voice to my research participants and allows the reader insight into their reflections on their personal and lived experience. Phenomenology has been used and developed in the area of sexual health by Professor Paul Flowers of Glasgow Caledonian University.⁶ There are many parallels between the work he has undertaken with men who have sex with men, some of whom are living with HIV, and my area of interest. Although he is a health psychologist rather than a theologian, the subjects for his research have much in common with mine (and some are the same people) and his work embraces many of the sensitive areas that I have had to address, such as the impact of HIV on sexual behaviour and choices. He has modelled a way of working with individuals to understand the impact of an external phenomenon on their personal and often private lives. His work gives me confidence that this is an appropriate way to approach the research. It protects the participants as they are very much in control of the interview process and it ensures that the material I collect is managed in a robust and appropriate manner. Working within a phenomenological framework allowed me to gather personal testimonials and to ensure that the participants were able to speak for themselves, to share their own stories.

⁶ <https://www.gcu.ac.uk/hls/staff/professorpaulflowers/>

Hans-Günter Heimbrock, in a lecture he gave at Boston University entitled 'Practical theology as empirical theology', addressed the question of data collection within practical theology, recognising that it is important to ensure that the resultant findings are robust (Heimbrock, 2008). He referred to the work of David Plüss who addressed that question by suggesting that practical theology should concern itself with 'phenomenology, hermeneutics and action oriented theory' (Plüss, 2008). These theologians are proposing a model that has sufficient intellectual rigour to stand alongside other ways of doing theology. Their thinking concurs with the work that has been undertaken by Professor Flowers, giving me even more confidence that this methodology offers the broad framework required for my study.

1.5.6 Hermeneutics

Hermeneutics, interpretation theory, is central to the practice of theologians, who interpret and contextualise scripture and other theological and literary texts.

The term is used to describe the relationship between scripture and the reader. It is described by David Jasper in *A short introduction to hermeneutics* as:

[A]bout 'interpretation' or even 'translation', and especially the interpretation of sacred texts, which believers may understand as in some sense divinely inspired or 'the word of God' (Jasper, 2004:7).

Other disciplines have engaged with hermeneutics as a philosophical underpinning for a variety of texts, from historical work to literary writing. The hermeneutic approach is important here to help us understand the personal stories in a contextual way. These are not just stories of people who have been directly affected by HIV, they are the distinctive stories of people who have been affected by the Edinburgh HIV narrative. By reflecting on and thus interpreting the narratives, we are enabled to acquire a deeper understanding of the lived reality and the impact on the life journeys of the people concerned.

Swinton and Mowat comment on hermeneutics:

[W]e would want to argue that hermeneutics is what people are, that is, human beings are by definition interpretative creatures. In other words, hermeneutics is an ontological rather than merely an epistemological position (Swinton and Mowat, 2006:107).

Swinton and Mowat have helped me to name what is particular about this approach and, indeed, about my ministry. As an ordained person working within a secular agency, I have been able to offer care and support with a clear therapeutic intention. I have used my counselling skills, training in techniques that have been designed for this client group, for example Motivational Interviewing, and knowledge of HIV, to support the service users.⁷ None of that differs from what my colleagues are able to offer. The 'added extra' is the spiritual dimension, the ability to reflect on the ministry and to apply that reflection to my professional practice. The intervention is then transformed from an attempt to offer help to an attempt to model a Christ-like approach to each person and every situation.

I come to my research with a perspective and opinions formed over the years I have worked in the sector. The hermeneutics offer a safeguard against being totally blinkered by these limitations. Swinton and Mowat use the work of German philosopher, Hans-Georg Gadamer, author of *Truth and Method of Hermeneutics* (Gadamer, 1960), to illuminate this:

Gadamer's key point here is that we must become aware of our own embeddedness or historical situatedness and constantly reflect on the ways in which this situatedness influences the way that we interpret our world (Swinton and Mowat, 2006:110-111).

Recognising and acknowledging the context and our own place within that context is key. The information we gather is dependent upon its socio-cultural context and it is from a starting place of honouring that context that we are able to make any plausible sense of the data. Interpretative experience is of more interest than interpretative method; our understanding is inherently linked with our experiential learning.

The introduction of hermeneutics into my modelling is supported by another scholar, Stan Lester, who suggests that pure phenomenology seeks to describe rather than to explain. He recognises that it may be necessary to include

⁷ Lothian Health encourages training in Motivational Interviewing for sexual health and HIV professionals.
<http://www.lothiansexualhealth.scot.nhs.uk/Professionals/Training/MotivationalInterviewing/Pages/default.aspx>

another facet, suggesting that ‘adding an interpretive dimension ... allows it to inform, support or challenge policy and action’ (Lester, 1999:1).

Lester is noting that simply to recount without interpretation is an undertaking that will have limited value. In my situation, I am very keen to allow the narrative voices to be heard and to take centre stage, but I am also aware of my responsibilities as a researcher to reflect on the material I have gathered, to attempt to draw out the commonality and the differences between the lived experiences and to offer some reflexive learning for the reader.

1.5.7 Hermeneutic phenomenology

An approach which has come to be known as hermeneutic phenomenology was developed by Martin Heidegger. Heidegger was a student of Edmund Husserl whose work gave him, and in turn gives us, a good grounding in basic phenomenology. Susann Laverty in her paper, ‘Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations’ describes Husserl as being ‘interested in acts of attending, perceiving, recalling and thinking about the world, and human beings were understood primarily as knowers’. By contrast, she describes how Heidegger’s focus was on *Dasein*, a German word which has no easy English equivalent but is translated by Laverty as ‘the mode of being human’ or ‘the situated meaning of a human in the world’. Laverty is helping us to see the development from an understanding of the human condition as ‘knower’, that is intellectual processor, to a broader definition which incorporates the individual’s sense of their own being and place within the world, to an experiential form of understanding.

Sally Brown, in her chapter on hermeneutical theory in *The Wiley-Blackwell Companion to Practical Theology* defines Heidegger’s theory:

[T]o be is to be engaged in the world of experience, and human beings know themselves only through experience and as embedded in a world (Brown, 2012: 114).

Husserl developed his method of phenomenology in order to better understand the ways that people respond to their place and situation in the world from their own perspective of self knowledge and lived experience. Heidegger understood

from Husserl that individuals are the experts in their own world but he observed that their experience informs their future decision-making and consequent actions. The hermeneutic, the reflection on consequences, and the subsequent decision to act differently was, for Heidegger, a response to a world that was often challenging. For Heidegger, people learn and then process that learning, leading them to make conscious choices and to feel that they have some control within their lives.

Readers will see in the transcribed oral histories that reflective learning has been important not just for me as a researcher, but also for the participants in this research. In particular, section 4.4 on personal determination allows us to see the impact on decision making of learning from personal reflection.

1.5.8 Interpretative Phenomenological Analysis

Heidegger's approach has been further developed by Smith, Flowers and Larkin in a model that they have called 'Interpretative Phenomenological Analysis', which is abbreviated to IPA (Smith, Flowers and Larkin, 2009). Their work is interested in significant change in people's lives and offers some answers to the limitations recognised by Lester. It allows for the material to be gathered in line with phenomenological methods and then adds on a tool for analysis, thus allowing the researcher to engage with their material in a comprehensive way. The method fits with my aim to both tell the story and to allow room for reflexive analysis of the data. It meets Plüss' requirements for a robust model within which to practise practical theology.⁸

The introduction to Smith, Flowers and Larkin's book describes the model:

IPA is a qualitative research approach committed to the examination of how people make sense of their major life experiences (Smith, Flowers and Larkin, 2009: 1).

They describe the goal of IPA as follows:

It can be said that the IPA researcher is engaged in a double hermeneutic because the researcher is trying to make sense of the participant trying to make sense of what is happening to them. This captures the dual role of the researcher. He/she is employing the same mental and personal skills

⁸ See 1.5.5

and capacities as the participant, with whom he/she shares a fundamental property - that of being a human being. At the same time the researcher employs those skills more self-consciously and systematically. As such, the researcher's sense-making is second order; he/she only has access to the participant's experience through the participant's own account of it (Smith, Flowers and Larkin, 2009:3).

The starting place for IPA is phenomenology and then it draws upon hermeneutics and ideography to further develop the methodology. Ideography is an approach used within psychology. The word derives from the Greek *idios* which translates as 'own' or 'private'. It is concerned with the individual rather than the general. Ideography encourages an emphasis on detail and therefore ensures that the researcher remains focussed on deep analysis. This is important in this research as the sample size is small, but the interviews were intense (lasting on average sixty minutes) and include sharing at a deep level by the participants. Ideography has encouraged me to draw out that which is held in common within the interviews, for instance, in finding experiences from professionals that support and elaborate the personal stories given by participants whilst continuing to see each personal story as distinctive and unique.

An important feature of IPA is its approach to analysis of the data. Substantial weight is given to the narrative material that has been collected and to the reflective analysis of that data. The instructions to the researcher are unambiguous:

[T]he results section of the IPA write-up is much more substantial, and much more discursive, than the results section of a typical quantitative report. A large proportion is constituted by transcript extracts whilst the remainder is your detailed analytic interpretations of the text. Your purpose here is twofold: you need to give an account of your data, to communicate a sense of what the data are like, and you need to offer an interpretation of your data, to make a case for what they all mean (Smith, Flowers and Larkin, 2009:109).

In line with this recommendation, chapters three and four contain significant transcript extracts, followed by interpretation and reflection. IPA is a model that makes sense in my field of study and which offers a robust framework within which to share the oral histories that I have gathered. There is a deliberate intention to encourage reflective engagement with the material that has been gathered, enabling a detailed examination of lived human experience.

This model allows me to fully honour the stories that have been shared, whilst applying intellectual rigour to the analysis and learning that follows.

1.6 Core sources of historical information

Research has been undertaken by others on the history of HIV in Edinburgh, a city with a particular story that focuses on injecting drug users and drug enforcement policies in the early 1980s. I will refer in particular to the MD thesis of Dr. Ray Brettle (Brettle, 1995), one of the infectious diseases consultants who became involved in HIV work in the earliest days of the epidemic. Helen Coyle's PhD thesis explores the responses of policy makers to the Edinburgh HIV epidemic (Coyle, 2008) and Neil Olley's PhD thesis (Olley, 2003) looks at the history of drug policy within the city. Brid Cullen was the manager of a local Roman Catholic support charity in the 1980s and early 1990s and published a book which captures first person accounts (Cullen, 1999). Judy Bury who was the primary care facilitator (HIV/AIDS) for Lothian Health edited a book with colleagues which addressed the medical, social and counselling issues for women living with HIV in Scotland, and much of her material derives from the situation in Edinburgh (Bury et. al., 1992). None of these publications takes a theological approach. Brettle and Cullen both tell personal stories, but offer little reflection on those stories. Coyle and Olley tell the history, mainly drawing on archived material such as the minutes of meetings and reports of working parties. Bury shares a collection of essays that offer an overview of the situation in the early 1990s.

My work, grounded as it is in personal story, tells the history in a different way. It relies, of course, on memory and it could be argued that each person's story is of necessity only partial. However, collectively those stories support one another and create a picture that is bigger than the sum of its parts. The analysis I apply ensures that the material forms a robust source. Oral history is an area of resurgent interest, often focusing on cultural identity. For example, the School of Scottish Studies based at the University of Edinburgh has a remit to 'collect, preserve, research and publish material relating to the cultural traditions and folklore of Scotland' (Institute of Historical Research, 2008). The work of that School gives validity to the approach I have taken. My small project

gathers and shares the stories and memories that form the social history of a group of people who lived in a particular place at a particular time and were affected by a virus.

Additional material has been sourced through the Lothian Health Services Archive, which is held at the University of Edinburgh. Documentation relating to HIV in Edinburgh and Lothian from both health and social care perspectives has been gathered and catalogued. It is a rich source of contemporaneous material. It must be remembered that written material, however accurate the minute taker or author of a report may be, can only offer a partial perspective. Minutes of meetings report that which was considered to be most important at that time; with the benefit of hindsight it may be the case that important strands were overlooked. I suggest that the oral histories I have gathered stand alongside the written material from meetings and discussions that were held at the time and that each has a significant and equal value.

1.7 Other relevant recent research within Edinburgh

A research project was undertaken by the Scottish Government in March 2011. This was a piece of work that aimed to better understand, and to seek ways to address, the issue of HIV related stigma. The resulting project was 'HIV Always Hear', a pack of educational materials designed for use by schools and churches (HIVAlwaysHear, 2013). The initial set of transcripts was published by the Scottish Government in a document entitled 'HIV testimonials'; I was granted permission to quote from that material where it was appropriate. I have used a small amount of the material to support data that I have gathered. It is apparent from the HIV testimonials data that my assumptions about the depth of material that I was able to collect are correct. The testimonials tell the stories in a particular way and with a distinctive focus on living with stigma. They share meaningful material but it lacks the "thickness" of description which arises out of the connections and relationships I have made.

Having considered the framework and methodology for my research, I will now explore the pertinent ethical issues.

1.8 Ethical considerations

Ethical permission for this research was granted by the University of Glasgow College of Arts ethics committee. I created a 'participant information sheet', a plain English explanation of the aims of the research and the ways it could be used in the future, clarifying that material might be used in future publications both in print and online. This was shared with all participants. I also created a written 'consent to the use of data' form.⁹ It acknowledges the right of the participant to be identified as the copyright owner of their interview and offers the option to be identified either by name or pseudonym. This choice is recorded on the form. I invited participants who wished to use a pseudonym to choose the name I would use. Part one of the consent form gives permission for the recorded interview(s) to be transcribed and used within the dissertation and other work that may be created by the author. Part two allows for the recordings to be shared with the Lothian Health Services Archive. The archivist is actively engaged in an oral history project, seeking to record and store the stories of people living with and directly affected by HIV in Lothian. My participants have the option to share their stories in this way or to decline the invitation. Access to material stored in the archive is controlled by the University of Edinburgh's policies on access to data and is strictly regulated.

The tapes on which the interviews were recorded have been transferred to a password-protected computer. The transcriptions are stored in the same way. Permission forms are stored in a locked filing cabinet. I have undertaken to store this material safely for ten years at which point it will be destroyed.

I am conscious of the potential pitfalls with my approach to this piece of research. There is a clear power imbalance between me and the Waverley Care service users whom I interviewed. There may be unspoken agendas, for instance a desire to please, which may have interfered with the collection of honest data in the form of personal story telling. In particular, the service users I interviewed have all made funeral plans with me and have an expectation that I will be involved with them at the end of their lives. I was aware that this dynamic could make it difficult for them to decline the invitation to participate in my research. I managed this risk by ensuring that a colleague from Waverley

⁹ These documents form appendix 2

Care checked with each service user that they wished to participate and ensured that they understood that they could stop the interview at any time or ask for sections of the tape to be deleted. I undertook to ensure that any ethical considerations that arose were discussed in my supervision, both within the University and within Waverley Care. Gillian Bolton makes it clear in her discussions of reflective practice that this is an important consideration:

Ethical and power issues need addressing in supervision, particularly if the supervisor is also in a position of authority over the practitioner, who may be justifiably cautious about disclosure (Bolton, 2010:61).

I realised very early in my studies that my situation as both researcher and day-to-day participant in the lives of my subjects is delicate. There is clearly the potential for an abuse of the power imbalance or, even more insidious, the potential to manipulate pastoral situations in order to elicit suitable data for the written work. Inevitably, my pre-existing relationships with many of the research subjects will impact on my observations. Similarly, their willingness to share experiences and perceptions will, I hope, be influenced positively by that pre-existing relationship.

I put safeguards in place in order to ensure that participants were able to give informed consent and to do what I could to avoid the inadvertent abuse of subjects. I guarded against the pitfalls I was able to identify by making the research requests to service users in a way that gave genuine permission to refuse. I ensured that simply written material was available, describing the intention of my research and the ways that any material gained in interview would be used, how it would be stored and who might have access to the final dissertation. I was as clear as possible that there was no requirement to participate and that my pastoral relationship with a service user would not be changed by their decision on whether or not to participate. A safeguard was put in place by seeking the support of a colleague within Waverley Care. I approached the individual I proposed to interview and talked them through the written information. I gave them time to consider my request. I then asked my colleague to go over the paperwork with them and to support them to make an informed decision.

As a qualitative researcher, I am not alone in choosing to present my data in a way that I find helpful. For instance, some have chosen to present visual work (film, artwork, embroidery etc.) and others to share their work through the medium of the creative arts. This cannot be a value-free process. Decisions are made about what to include and value judgments will inevitably be made on which are the most interesting or valuable pieces of data. My theological reflection emerges from my own spiritual life, having its grounding and values deeply implanted in that life. I will use my reflective diary as a resource to enable me to make the best possible choices about what to include and how to present the information I have gathered. This approach shares something with artistic impression, for example film-making, as an academic discipline. Ethnographic filmmakers clearly share some of the challenges faced in this research. In his book *Ethnographic film: revised edition* Karl Heider is clear that the most important stage in his process is the ethnography which can then be followed by the making of a film which tells the story and shares information in a visual way (Heider, 2006:112). Similarly, ethnography which emerges from my privileged position with my service users will lead to the collection of unique data. It will then be my responsibility to share that data in an appropriate and accessible way.

The reflexive focus of my work will, inevitably, be influenced by my own experiences and observations. I have amassed understanding and interpretations over the years which have become integrated into my personal ways of reacting and responding. This bias will colour the research. However, my awareness of these influences will, I hope, mitigate the potential problem. There is an ongoing and constant process of observation which has been described by Hester Parr in her work with people experiencing mental health problems. She uses the term covert ethnography which she defines thus:

My use of the term 'covert ethnography' can be understood to signal a process of participating with, and observing, peoples and settings, without informed consent, for the purposes of research (Parr, 1998, 29).

She goes on to explore the ethical dimensions of this approach saying:

It is not assumed that there is a strict ethical dividing line between overt (open and consensual and therefore 'good') and covert (non-consensual and therefore 'bad') ethnography. Both research methods involve complex personal positionings (when 'doing research' and 'writing research'),

differing 'explanations' of the self, immersion in local geographies, and observation and recording of ethnographic materials (Parr, 1998:29).

My situation is perhaps even more complex as my relationships with people are both as researcher and source of pastoral support. From the perspective of my then employer, Waverley Care, the role of researcher would always take second place to the primary focus of my role which was the interaction with people, with a distinctively person-centred focus. One justification for the research is that it endeavours to honour people living with HIV in Edinburgh and to ensure that their unique stories are not lost or left untold. The existence and focus of the research has not been hidden from service users; however, the reality is that most of the time they are not very interested in the detail of permission protocols. This means that I have an additional responsibility to ensure that they are giving informed consent. The lack of concern can be seen in the following quotation from a conversation with a man who was physically unwell and had given verbal permission for his story to be used within my written material. He said 'I don't need to sign all this paper and that... I ken you and I trust you'¹⁰.

I have described the decision-making processes that I have undertaken in order to define the parameters of my research. I have chosen Interpretative Phenomenological Analysis as my research methodology and I have taken careful note of the ethical considerations that might arise. My actual experience of conducting the interviews and subsequent informal conversations about my research have been very positive. Service users are very interested, including some who have not been interviewed, and they appear to have taken some ownership of the finished material. Service users regularly ask about the progress of the work. One woman has told me that she can't die before I graduate!

1.9 Naming my role and its remit

There is a difficulty for me in finding the appropriate nomenclature for the role which I fulfilled. At times in my career with Waverley Care I was described as

¹⁰ 'Ken' is Scots for 'know'. In conversation with the author, October 2012.

Chaplain, Spiritual and Pastoral Care Co-ordinator, and Spiritual Care and Faith Communities Co-ordinator. Each of these titles attempted to describe the role at a particular time. My initial employment as a chaplain was a reasonable description of the role at that stage. In 2000, Milestone House was a hospice and the chaplaincy task was focussed entirely in that place, offering support to service users, their loved ones and the staff team. People were still dying from HIV related illness and much of the work was around end-of-life issues. It was intensive and longer-term than in a more traditional hospice setting, where the average end-of-life stay can be counted in days. People would die over a period of weeks and the family, and sometimes the extended family, would spend a significant amount of time in the unit. After the funeral there might be some bereavement support and then there would be only occasional contact, perhaps on the anniversary of the person's death, or on World AIDS Day. This fits with a description of chaplaincy as a ministry of presence. Miranda Threlfall-Holmes and Mark Newitt explore the core elements of chaplaincy in *Being a Chaplain*:

[...] a sacramental ministry, not primarily in the 'churchy' sense of celebrating the sacraments but in the theological one of taking the everyday stuff of life and making it a sign of God's presence and love. It is also an expectant ministry, waiting for opportunities to present themselves and expecting those opportunities to come (Threlfall-Holmes and Newitt, 2011:xvi).

1.9.1 Chaplaincy within the hospice setting

A document defining the values of the chaplaincy service within Milestone and dated August 1994 shows how from its earliest days the service was seeking to offer something of value to people regardless of their own belief system. It is interesting to note that there is no mention of God and only two uses of the word 'spiritual':

- We operate from a value base of honesty, truth, compassion, courtesy and love
- We accept and affirm people as they are and do not try to change them
- We support people in their spiritual journey
- We encourage and support people to make their own decisions and life choices
- We value and promote the skills and gifts of people

- We provide a sensitive response to the invitation of the individual to share in their spiritual/life and journey. We respect and value the privilege of this invitation to share.

This document, written by those who were working as chaplains within a hospice setting, shows how cautious they were in their use of language and their offer of support. Perhaps the most important point is the final one which emphasises that any engagement would be in response to an invitation offered by the service user. There was no expectation that people would issue such an invitation.

This was the foundation upon which my ministry of presence in Milestone was based. It was very clear that service users were in control. Jane Millard, the first chaplain at Milestone, once told me that she felt the gift we had to offer was that we gave the service users, particularly those who were resident within the residential unit, something that they could control. We were the only staff who could be asked to go away. She explained that someone who was sick and confined to their bed had no option but to see the doctor and the nurses and the domestic staff. Each of them had a role which was necessary for the person's comfort. But the chaplain was an optional extra and we offered people something significant when we gave them the power to choose whether or not they allowed us into their rooms. To make myself known, I spent time with service users in the public areas, perhaps over afternoon tea. I would have meals with service users and families, would join in with communal activities wherever possible and generally make sure that people knew who I was. Other service users would often introduce me to new service users or to family members. They would usually say something like 'Marion's the chaplain but she's OK'. That recommendation made a huge difference in dealing with any suspicion there might be and allaying fears that I would want to talk about religion. When I introduced myself to new people, it was not uncommon for them to immediately say 'I'm not religious' in an apologetic way. My task was to reassure them that my interest was not in their belief system but only in whether I could offer them some support at that particular time in their life. This approach to chaplaincy is supported by Jonathan Hatgas in his paper

Prophet at the bedside: a model for hospital chaplaincy where he discusses one of the tasks of chaplaincy in this way:

The revelation of God's presence may simply be through the work of empathetic listening, that is, of being present to and acknowledging the situation at hand. Sometimes, the larger the crisis and the more emotions at play, the less words are needed. It could be that all that is needed in these situations is the presence of someone who cares enough to be with the family (Hatgas, 2016:4).

This was a group of people who often felt that no-one cared. They might have been ostracised by their family or by neighbours. They were likely to be living in fear of being 'outed' as someone who was living with HIV. Annie supports this idea when she spoke about seeing people in the HIV clinic who then ignored her within the community in order to protect their anonymity. I had a similar experience. I accompanied someone to a clinic appointment and caught sight of a member of the congregation I was serving at the time. He jumped up and ran to hide and I pretended that I had not seen him. I was filled with deep sadness that I was experienced as a threat to his anonymity. Over time, I gained the confidence of most service users and even began to see people who did not use Waverley Care services but were willing to have an engagement with me.

A definition of what I had offered to people was given to me by a Buddhist service user at the end of my time at Waverley Care. He gave me a gift of his figurine of Tara from his personal shrine. He described Tara to me as one of the Bodhisattvas in Tibetan Buddhism. He told me that she represents compassion, both motherly compassion and active compassion. This is what he said '[Y]ou have been a Tara for the HIV community in Edinburgh for so, so long...'. That is good evidence that it was possible to offer deep support to people of different faiths, that I had clearly managed not to impose my own theology on others, and that the contact was appropriate.

1.9.2 Chaplaincy as outreach from faith communities

Mainstream faith communities have traditionally supported 'outreach' into the community and especially into those institutions that deal with people who are at points of change or crisis in their lives. Prisons, healthcare settings, schools, universities and, increasingly, large workplaces may offer access to a chaplain. Some of those settings, for instance hospitals, employ chaplains directly. Others

such as newer universities may allow denominations to offer chaplaincy support within their institution, but might not have prioritised chaplaincy as a service they would support financially. Newer models of chaplaincy, for instance workplace chaplaincy and arts chaplaincy, usually work across a number of venues, each of which would have some degree of ownership of the service.¹¹ To a large extent, this model of chaplaincy is one of crisis intervention. The chaplain has a presence within the institution, building trust with the people they encounter and is therefore available to deal with crises as and when they arise. In healthcare settings, these will often be of a life changing nature. There will be a lot of general conversation and relationship building, but in terms of intensive work the model assumes brief, often one-off interventions which offer something profound that stands alone. Chaplains are almost always associated with particular places, usually institutional buildings, and work within a defined geographical context. In some settings, notably schools and to some extent prisons, longer-term relationships are developed. They are, however, time limited; young people leave school, almost all prisoners are eventually released. The work at Waverley Care was essentially a lifetime commitment to people living with HIV, an expectation that we were journeying together towards the person's death. Even after the introduction of effective treatments, mortality featured significantly for people. When I began to tell service users that I was leaving, they wanted to know whether I would still be taking their funerals. There is a security in knowing who will be conducting a funeral and that it will be in a style that they know and understand. That is of real importance to the people I ministered amongst.

A tangible example of this occurred two months after I had left Waverley Care. I received a phone call from a service user who made a funeral plan with me some time ago. He is currently undergoing cancer treatment and had only just heard that I was no longer at Waverley Care. He was upset and panicking, anxious about who would take his funeral and seeking reassurance that his service would not be conducted in an anonymous way by someone who did not

¹¹ See for instance Work Place Chaplaincy Scotland: <http://www.wpcscotland.co.uk/>

know him. I was able to reassure him that, so long as I am able, I will conduct his service. The relief was palpable.¹²

1.9.3 Working as a chaplain

In the early days in the life of Waverley Care and the lives of people living with and affected by HIV in Edinburgh, a chaplain was exactly what was required by those for whom the treatments had come too late. There was a geographical base for the work within the dedicated hospice at Milestone, and a steady stream of people whose health was declining and who could be supported to prepare for the end of their lives. Christopher Moody describes this as a ‘wilderness ministry’, that is a ministry that is exercised where people are (Moody, 1999:16). In the Milestone situation, initial introductions were often opportunistic in nature, presenting the chance to meet new people in as non-threatening a way as possible. It was important to be sensitive to the possibility that an introductory encounter would raise anxiety, especially about the parameters for any engagement. People worried about what they could ask, what they could say, whether they would be judged and whether their views and beliefs would be respected. Both chaplain and service users would be unsure about what to expect and there might be pre-conceived ideas on both sides. As chaplain, it was never possible to pre-empt the conversation or to anticipate whether or not one would be welcomed. People whose previous experiences with a faith community had been difficult or damaging were inevitably very suspicious. Some people needed more time than others to prepare, to feel confident enough to begin the conversation. Some needed several informal contacts in order to build confidence and trust and some people never managed to have end-of-life conversations, perhaps convincing themselves that if the conversation didn’t happen the outcome it anticipated would not happen either. Moody notes that inhabiting this territory as a workplace for ministry is challenging for the chaplain. They are on secular ground, alongside the people with whom they are journeying and they are subject, with them, to the demands of that secular space (Moody, 1999:16-18).

¹² Phone call 28:06:2016

I placed great importance on supporting people to make end-of-life plans. They were unable to control the impact of the HIV virus in their body or to have much say over where and when they would die, but they were able to make very detailed plans about what would happen at the end of their life. We discussed what people would wear in their coffin, who they would want to be seen by, whether they wanted items to accompany them in the coffin and the detail of their funeral service. For many service users, music had been an important feature in their lives and the choice of funeral music was one that took up much time and often extended to several discussions. As new music was created by favourite artists, changes would be made, some inevitably more appropriate than others.

Our understanding of HIV developed and medical treatment improved, which meant that new priorities emerged for people who were infected. By the time I began work at Waverley Care (2000) it was clear that effective treatments were becoming available and that many people were having a positive response to them. People who were using Milestone for respite were not always physically unwell but were often seeking respite for social and psychological reasons and the engagement with any kind of spiritual care needed to be based on something other than end-of-life planning. What began to emerge was a ministry that was different from most chaplaincy:

Chaplains will not often get to follow the lives and careers of those they interact with at significant moments. We often only see people once or at most for a few years, and rarely get to see the seeds we have (it is hoped) planted, watered or tended come to fruition (Threlfall-Holmes and Newitt, 2011:xvii).

It was becoming clear that the relationships with people were going to be regular and over a much longer period of time. I already knew some of the Milestone service users from previous places of work and the relationships I made were built on those foundations. This was not a limited or occasional engagement but something that would continue over a number of years.

1.9.4 Spiritual and pastoral care co-ordinator

In 2002, Milestone ceased to function as a hospice and the remit for the work there changed. The unit became a respite centre, taking people for relatively

short stays, usually two weeks, on a regular basis in order to support them to manage their lives within the community. In response, my role changed. A new job title emerged of spiritual and pastoral care co-ordinator. The connections with people became more like those of a parish priest ministering to a gathered congregation. People would have respite stays in Milestone when they would re-establish contact and perhaps embark upon a piece of healing therapeutic work. If that work was not completed by the time they were discharged, there would be follow-up home visits. Over a number of years, service users began to see the opportunities for engagement with the spiritual and pastoral care service and they started to initiate contact even when they were not using Milestone. My mobile phone number was available to service users and I was on-call to them. On the whole people did not abuse that facility. If they were looking for support they would be likely to send a text message asking me to contact them when it was convenient. They knew, however, that they could call in a crisis and that I would respond. During this period of time, the work continued to be centred on service users, their loved ones and the staff teams within Waverley Care. It is worth noting that there was contact with staff on a fairly regular basis. They would bring issues that they did not feel able to take into line management supervision. For instance, one younger woman became concerned about her alcohol consumption and wanted to speak to someone about her lifestyle. Another needed to discuss childhood sexual abuse after she had spent time with a service user who was discussing abuse and it triggered memories from her own life. The emphasis was on healing in the most holistic understanding of that term.

I began to work with gay men, looking at the damage that had been inflicted upon them by their faith communities. My starting place would be to attempt to help those men to see that God continues to love them and that the negative messages they had heard were not of God. During this time I heard confessions from several service users, baptised some, blessed many and began to build trusting relationships. It became commonplace for a service user to approach me simply for a blessing. A number asked for a bible, a rosary or a book of prayers. Engagement with scripture or a prayer life were, of course, not the primary aims but they became regular outcomes. Service users would often ask theological questions, about the Trinity, about my understanding of Heaven,

about my own prayer life. It was perhaps important to the building of relationships that I always prefaced my answers by saying that I had no need for them to share my beliefs but that I was willing to talk about my own spiritual life and to give my own perspective on these existential questions. For instance, I would answer any question about life after death by saying that I could not offer any certainty but I could share my own understanding and beliefs. So, although there was no liturgy or formal teaching of the faith, there were many informal conversations and discussions which created opportunities to make faith meaningful and relevant to people.

1.9.5 Spiritual care and faith communities co-ordinator

The next stage in the development of the role was for it to become more outward facing. There was another change of title, to spiritual care and faith communities co-ordinator. Initially, the outreach work had a focus within the African-led congregations in Scotland. Waverley Care was beginning to explore ways of working on HIV testing and prevention with Africans and it became clear that these churches functioned as *de facto* community centres for their congregations. Church was a place where people could meet others who spoke their mother tongue and who had shared cultural values. I began to make contacts with African pastors; at the time (2006) there were around fifteen African led congregations in Edinburgh and a much larger number in Glasgow. As a faith leader, I was able to address some of their anxiety that Africans were being targeted or discriminated against and I was invited to address a number of congregations during their Sunday morning worship. This allowed me to talk about the importance of testing in order to know one's HIV status, the importance of engaging with medical services and of taking medication as prescribed. We had heard about churches, mostly in London, that were encouraging people to stop their medication in favour of prayer, believing that God would heal. I was able to talk with the pastors about their understanding of healing and to suggest that God was equally at work using the gifts of scientists and medics who were developing new and effective treatment.

As the work of Waverley Care expanded, so did this aspect of the role. I began to work with Muslim communities and to speak within the wider church, especially seeking to challenge stigma. In 2010 Waverley Care was

commissioned by the Scottish Government to produce materials addressing the issues of HIV related stigma. The resultant project, HIV Always Hear produced materials both on-line and in hard copy. The first of these were module style packs containing targeted material for schools and churches.¹³ I was involved in the delivery of that material in a number of settings.

It is worth noting that there are many gay men living with HIV who live healthy and fulfilling lives and whose sexuality and HIV status do not define them. They are not the people who use support services on a regular basis. They are people who engage with clinical services and might access advocacy and information support when necessary, but who do not need or have any interest in the more intensive support services that I have worked within. My engagement with some of those men has been when there has been a death, but that has been more of a functional role - I have met with the bereaved partner and loved ones and conducted a funeral and then had no ongoing contact, because there was no need. This is perhaps an example of ministry that is similar to parish work, being available to a community but not necessarily having regular contact.

1.9.6 A distinctive ministry

Returning to a focus on the people who use Waverley Care services, they are a group for whom isolation and loneliness are issues that are regularly identified as problems. When Milestone was being re-provisioned in 2014, I was involved in service user consultation on what would be most desirable in the make up of services. Time and again, people spoke about the loneliness they felt, especially in the evenings and at weekends. Many service users have been bereaved of their partner and have not found a new relationship. They live alone, often with limited financial resources (a situation which is worsening with the changes to disability benefits that are being introduced by the Government) and have become dependent on support services for their social contact.¹⁴ They

¹³ www.hivalwayshear.org

¹⁴ Many people living with HIV have been significantly affected by the changes in eligibility for certain benefits. <https://www.gov.uk/government/publications/2010-to-2015-government-policy-welfare-reform/2010-to-2015-government-policy-welfare-reform>

are the people to whom I hoped to show a glimmer of God's love, people for whom a sense of presence in their lives, however tenuous, might bring a little comfort. By the time my post came to an end, my working life was divided between (often intensive) one-to-one engagement with individual service users, facilitation of peer support groups and outreach into faith communities where the focus was on testing and prevention.

I have shown that there were times when chaplaincy was a helpful label and times when the role could justifiably be seen as such. I have also shown that there were ways in which the ministry within Waverley Care was very different from chaplaincy: the engagement with people was long-term; the role was based both within the agency and within the community; there was a significant outreach ministry to the wider community; and there was an expectation that, as chaplain, I would be involved in many of the day-to-day aspects of the service. This latter point can be evidenced by, for example, the times when I accompanied people to appointments because no-one else was available, the times when I functioned as a support worker because the unit was short staffed, the times when I organised events because no-one else was available or had the necessary contacts. The longer-term engagement and accessibility to people has something in common with parish ministry, as does the multi-tasking nature of the role; the difference is that this community rarely gathered in one place at one time (the exception being an annual World AIDS Day event which was very well attended), there was no overt expression of Christian worship and only occasional teaching or exposition. Pastoral care was a useful label, but limited in its scope. There was pastoral care but there were many other aspects alongside. It was also a ministry with some of the most stigmatised and marginalised people within our community. I spent many of my working days with people whose lives had been focused on drugs and/or sex work or who had found themselves discriminated against because of their sexuality.

1.10 My personal contribution to the role

It is perhaps the case that the difficulty I have encountered in naming this role emerges, at least in part, from the unique set of circumstances within which it was carried out. Not only were the environment and context unique (as will be understood further in chapter two) but I brought an unusual package of

experience and gifts. My career has been within the voluntary sector in which I have worked since the late 1970s when I was employed by Edinburgh Women's Aid, working with women who had experienced domestic abuse. In the 1980s I began to work with homeless people and over a number of years gained expertise in working with sexual abuse, sex workers, people with addictions and HIV. By the time I was ordained and moved to Waverley Care, I had considerable experience of working with people in the most troubled and challenging of circumstances. I then undertook my post ordination training with the chaplain at Edinburgh prison. Alongside this professional work, I was a volunteer bereavement counsellor and supervisor for fifteen years. The combination of theological training, ministerial formation and community-based work gave me a unique perspective on the lives and experiences that I encountered at Milestone.

This thesis has allowed me to share a unique story. HIV in Edinburgh has a particular story, that of a virus whose impact was most acute at a particular time and as a result of a particular set of circumstances. That impact continues to be felt. My role within Waverley Care was one of ministry coming out of a distinctive skill set and entering into the coincidence of time and circumstance that allowed something very special to emerge. In the next chapter, I will document the history of HIV in Edinburgh, the public health responses to the emerging virus, the faith community initiatives and the creation of Waverley Care, the locally based charity that came into being in direct response to the scale of the HIV epidemic within the city.

Chapter 2: Background and history

My intention in this chapter is to share in some detail the history of HIV in Edinburgh, a city that had a different epidemiology from other cities in the UK. In common with large cities across Europe and North America, there was an emerging epidemic amongst gay men in the mid 1980s. Unlike other large cities, there was a concurrent emergence of high infection rates amongst injecting drug users. The juxtaposition of these two groups of patients had an impact on the way that public health decisions were made and on the shape of the support services that were developed. I will describe the development of those support services with particular reference to the contribution of the churches, and to the growth of Waverley Care, which became the largest non-statutory service provider in the city.

I will show how decisions made by the police in the early 1980s inadvertently led to a significant epidemic amongst people who were injecting heroin. That epidemic was important not only in its own right but also because it affected distinctive communities in the more deprived areas of the city, resulting in extended families feeling the impact of the HIV virus in their lives. To document this aspect of the history, I will draw upon the work of two doctoral researchers, Neil Olley and Helen Coyle. Olley is interested in drug policy and charts the history of drug use in the city in the late 1970s and early 1980s. His work allows me to contextualize the emergence within Edinburgh of the cohort of people whose HIV infection can be linked with decision making by drug enforcement services. Coyle is interested in HIV policy making, focusing on the years between 1982 and 1994. That is a period of time before effective treatments were available and she provides valuable source material which shows how policy makers in both health and social work departments worked together to respond to the emerging crisis in their city. Both of these researchers tell the history primarily from written sources; in both cases they conducted their research some years after the events they are exploring. These are works of academic research which make a helpful contribution as I chart the territory within which my research is situated. There is also an MD thesis written by Dr. Ray Brettle, an infectious diseases clinician who was involved with HIV from the earliest diagnoses in the city. I will use his work to document the impact on the

medical profession and the strategies that they put into place in order to respond to the outbreak of infections that they were diagnosing. In addition to these sources, I have accessed contemporaneous written material, ensuring that I have as good an understanding as possible of the impact of HIV.

The data from the written materials that I have drawn upon will be augmented with verbatim accounts from the interviews I have conducted. I have been able to draw upon the memories of clinicians, other professionals and people living with HIV who have been involved since the mid 1980s. Their first hand accounts give a holistic view of the actual situation at the time when HIV was first introduced into our communities.

An underlying feature of my work is that I am sharing stories, capturing the experiences of the people who were directly affected at the time. That is one of the tasks of the chaplain - to get alongside people, to have a ministry of presence, to engage at a different level and to honour people for who they are and how they have experienced life. Thanks to the generosity of the people amongst whom I minister, I have been able to capture the social and spiritual histories associated with HIV in Edinburgh. By so doing, I am able to enrich the material that already exists and to offer a reflexive view of the impact of HIV within our community.

I have quoted verbatim from much of the source material that I have used for this chapter. That seemed important to me as I was very keen to give an honest flavour of the mood and the ways that people were thinking at the time. I have also used transcribed material from some of the interviews I conducted for this thesis. Biographical information about the interviewees can be seen at appendix one.

2.1 HIV in Edinburgh: the drug related story

The Edinburgh HIV story begins with the history of drug use within the city. From the late 1960s to 1979 the problem was primarily linked with stolen prescription drugs. A serving drug squad officer explained:

We had a large number of chemist shops broken into in Edinburgh. We had a team operating in Edinburgh of probably about up to twenty junkies

in those days who were capable of breaking into chemist shops (Olley, 2003:61).

Olley states that by the early 1980s there was a significant increase in heroin use in Edinburgh and elsewhere in the UK. He attributes this to political change in the Golden Crescent of South East Asia and regime change in Iran in 1979 (Olley, 2003:68).

This theory is supported by the research of two local General Practitioners, Roy Robertson and Kirsty Foster, who worked in a practice that saw many of the injecting drug users in the north of the city. They recorded an increase from approximately twenty patients in the 1970s to two hundred and thirty by June 1986 (Robertson, Bucknall and Foster, 1986:1216).

The increase in the availability of heroin in the early 1980s created a challenge for both criminal justice and medical services. Roy Robertson and Alison Richardson¹⁵ describe the problem:

The emerging crisis came in the form of increasing supplies of heroin, reputedly from Afghanistan and Iran in the wake of political upheaval in these countries. Excessive supplies in many European cities were evident and a shift of consumer from the student or dissident class to the socially deprived populations in inner-city housing estates gave a new profile to the problem. Medical services described damage done by injecting. Cases of hepatitis, abscess and endocarditis became common. Forensic pathologists noted a rise in sudden deaths in young people. [...]

As ever, and in retrospect, it is easy to see that there was a social change happening which was neglected and in some sectors ignored completely until much damage had been done. In 1980, however, a confident Government was uninterested in a compassionate response to a problem viewed as one of lawlessness and social disorder rather than a symptom of social malaise or a medical and public health emergency. The response was aggressive and authoritarian and completely missed the important warning signs that a humanitarian and medical crisis was emerging (Robertson and Richardson, 2007:491).

This quotation clarifies the political context. The Thatcher Government was in power and levels of inequality and poverty were increasing.¹⁶ The link between drug use and social deprivation is not disputed (Scottish Drugs Forum, 2007:7).

¹⁵ Dr. Alison Richardson was head of Clinical Psychology for Edinburgh HIV services from 1987 – 2008.

Robertson and Richardson go on to describe the emerging situation:

A practical and pragmatic response from a surgical supplies retailer in Edinburgh city centre was to sell, at low cost, needles and injecting equipment even in the knowledge that these would be used to administer illegal drugs. In September 1982, due in part to the prevailing political climate and resulting pressure from local pharmacies and general practitioners (GPs), the shop was closed. The ability of drug users in Edinburgh to obtain clean injecting equipment was consequently even more severely curtailed. Worse was to follow.

In 1984 the police and courts in Scotland's main cities were taking a new interest in drug misuse cases. [...] Lawyers and advocates reported individuals who were given long custodial sentences for small quantities of heroin which was clearly, in retrospect, for their own use rather than for sale to others for profit.

The numbers of heroin users increased. The heavy-handed response of the police, courts and the medical establishment, in their interpretation of the law and other guidance, served only to send injecting drug use further underground (Robertson and Richardson, 2007:492).

This situation was the backdrop to the arrival of HIV in the city. Olley shares the story of one drug user who was repeatedly stopped by the police:

What would be normal for drug users if they did have a syringe or an extra needle you'd wrap them up in toilet tissue then poke it in like a pen and just put it in the top pocket and hang on to it like that. If you got searched and taken down to the police station the police found them. They'd just drop them on the floor and break them in front of you and you'd be like that 'no come on, dinnae, it means I've got to look for all that and risk sharing with someone that's maybe got hepatitis. This is before AIDS'¹⁷ (Olley, 2003:144).

The service users I work with who were using heroin in the early 1980s have described their responses to the lack of injecting equipment. It became normal to share equipment, initially with the dealer, having a 'hit' on the premises with him, but more commonly to meet with other users and to have what might be described as 'shooting parties'. People have described to me how they would sharpen the needle that everyone was using and how news of new equipment would spread within the community. The most likely source of new needles and syringes at that time was when they could be stolen from a hospital. I have also

¹⁶ See, for instance: Poverty and Social Exclusion <http://www.poverty.ac.uk/editorial/more-unequal-country>

¹⁷ Quoted verbatim

been told about a fashion for ‘backloading’, one of many practices that arose around drug use which was believed to improve the experience. After injecting the heroin, the user would draw back a small amount of their blood into the syringe before passing it on to the next person. Thus users were effectively transfusing blood one to the other and creating the ideal conditions for HIV transmission.

2.1.1 Fear for the wider population

By 1986, there was real fear that there would be onward transmission into the heterosexual population from injecting drug users. Many of the women who were heroin addicts were known to work in prostitution in order to fund their ‘habit’ (and sometimes their partner’s habit as well). There was anxiety that sex workers would not be motivated to use condoms or would be willing to risk transmission in order to earn a premium from clients who preferred not to use them.

Writing in *Edinburgh Medicine* in February 1986, Dr. Ray Brettle speculated about the size of the problem:

The number of cases approximately doubles each six months which suggests that by the end of 1987 there will have been about 200 AIDS cases diagnosed in Scotland and on a population basis 50 of those will be in the Lothians.¹⁸ It has been estimated that for every one AIDS patient there are 25-50 infected individuals. There should therefore be around 100-300 such individuals in Scotland at present and by the end of 1987 we should expect 5,000 - 10,000 infected individuals (Brettle, 1986:11).

In the same article, Brettle gives a clear indication of the way those involved were thinking about public health and the need for health protection messages:

Spread into the heterosexual population may occur by bisexuals, prostitutes and drug abusers. The man in the street is still not at risk unless he indulges in promiscuity, prostitutes or intravenous drug abuse. Perhaps it is time for a health education campaign in Edinburgh to alert the drug addicts to the risks as well as other adolescents who may be considering drug abuse (Brettle, 1986:12).

¹⁸ At that time, there was not always a clear distinction made between HIV infection and progression to AIDS (Acquired Immune Deficiency Syndrome). The term AIDS is rarely used now.

The McClelland Report, *HIV infection in Scotland: Report of the Scottish Committee on HIV infection and intravenous drug misuse*, gives some factual information on the extent of the problem:

There were 795 reported cases in Scotland to June 1986. 64% were injecting drug users. Edinburgh had 60.6% of Scottish cases, 72.8% were drug users. (McClelland, 1986:17).

These figures show how infections amongst drug users were a significant factor in Edinburgh where almost 73% of cases reported in 1985 and 1986 were transmissions through injecting. This compares with injecting drug users comprising only 2.6% of infections in England and Wales (McClelland, 1986:6).

Anxiety about heterosexual spread continued into the 1990s. Writing in the *Medical Journal of Australia*, infectious diseases doctors, Ray Brettle and Philip Welsby, state:

The extremely slow progression of HIV infection makes it difficult for the average individual to understand the enormous threat AIDS poses to our society. Most HIV infected injection drug users are probably heterosexual and infectious from the time of seroconversion until death (perhaps 10-15 years) (Brettle and Welsby, 1991:634).

Dr. Gordon Scott, a consultant at Chalmers Sexual Health Clinic, reflected on this same risk factor:

One of the big concerns from quite early on, but it began to gather a bit of pace in the late '80s, was this potential bridge between drug use and the heterosexual population. The biggest risk with hindsight, I don't think anyone realised it at the time, was in regular relationships. If someone who is using, or has used drugs is in a regular relationship with either a female or male partner, that partner's at massive risk. In the early days nobody quite realised that the risk was cumulative. So one of the groups where there was the biggest concern was women who were drug users who were working as prostitutes to earn the money to pay for their habit, and often to pay for their partner's habit as well. And so [it was imagined that] there were lots of drug-using HIV-positive women, particularly down in Leith, who'd be happily having unprotected sex with all their clients, passing on HIV to the rest of the population and something must be done. To begin with I don't think Health [decision makers] really knew what to do and the first thing that I can remember apart from a lot of hand wringing and 'Oh my God, what are we going to do?' was the Centenary Project which was set up by the Church of Scotland Women's Guild¹⁹ (Scott, 2016).

¹⁹ An explanation of the work and genesis of this project is at 2.3.3

2.1.2 The introduction of harm reduction approaches

Responses to the realisation that drug users were disproportionately infected within Edinburgh led to creative thinking and the proposal that harm reduction measures, including free needle exchange and substitute prescribing of methadone (a non-injectable opiate) should be a priority. Dr. Philip Welsby made a more radical suggestion:

Will provision of methadone (in effect condoning oral drug abuse), needles and syringes (in effect condoning intravenous drug abuse), and education work? I doubt if we will ever know but undoubtedly they should be tried: the prevention of a few cases of AIDS will justify the expense. [...] Unfortunately heroin is a 'good' product. It sells well, profits are large, and demand high; some users are so satisfied that they resort to thieving or prostitution to obtain the product. There is only one counter to these market forces: undercut the product. [...] If we are going to condone oral drug use by giving out methadone, if we are going to condone intravenous drug use by giving out needles and syringes, then why not shake the earth a little more and supply IVDAs [intravenous drug abusers] with what they want - heroin - the purity and sterility of which could be assured? (Welsby, 1987:11).

My experience of working with drug users leads me to believe that Welsby's suggestion is sensible. People use drugs because the drugs work for them. Drugs help people to cope with whatever is unmanageable in their lives. Some drugs are legal and some are not - alcohol, for instance, is a legal substance. Heroin is an extremely effective drug for helping people to blank out traumatic memories and for relieving pain, both psychological and physical. Drug users will usually seek the drug that is most effective for them, and there is no doubt that heroin is the drug of choice for many people whose lives are dominated by their substance use and abuse. Substitute prescribing in Scotland usually involves methadone, a non-injectable syrup with a slow release formulation which means that a once a day dose is sufficient to prevent withdrawal. Methadone has some unpleasant side effects, it can cause sweating and nausea, and its formulation as a syrup has had a significant impact on dental health. Most of the drug users I know have lost all or most of their teeth. There is a sugar-free option available but most people tell me that the taste makes its use unpalatable.

I suggest that prescribing the drug of choice for people who are already addicted is a better harm reduction approach than prescribing a substitute that they are

likely to perceive as second best. They are less likely to ‘top-up’ with street drugs if they have access to their drug of choice as they will be using the substance that works best for them. This makes their drug use as safe as it can be. The evidence for this can be seen in the approach taken by Dr. John Marks, a psychiatrist who worked in the Liverpool area in the early 1980s. His clinic prescribed pure heroin and clean injecting equipment.²⁰ Despite the fact that Liverpool was an area of inner city deprivation with a high percentage of injecting drug users, HIV infection in the city was very low. This has been attributed to the radical practices of Marks’ clinic.

It seems that political considerations in Edinburgh led to a decision that a proposal to prescribe pure heroin would have resulted in a serious public backlash, whereas the methadone programme made pragmatic sense to most people. The decision was therefore made to implement a harm reduction programme based on methadone prescription and the availability of clean injecting equipment.

The Health Board announced a new approach to the treatment of drug users in June 1988 when Dr. Judy Greenwood was appointed to the new post of ‘consultant in the community treatment of drug abuse’ (*Edinburgh Medicine*, 1988, no 49:7). Dr. Greenwood had been involved in the establishment of a needle exchange clinic in Leith (in the north of the city) and in supporting and advising community based drug services. This appointment was not universally welcomed, as can be seen from the editorial in that same issue of *Edinburgh Medicine*. I reproduce it in full as it gives such a powerful flavour of some attitudes at that time:

Earlier this year four people had the bright idea of supplying the misfits in our society with cannabis, a relatively harmless illicit drug with no risk of hepatitis-B or HIV transmission amongst its users. They were imprisoned for a total of 41 years. The day they were sentenced the government announced that it was planning to make injecting equipment for intravenous drug users more widely available throughout chemists shops in Scotland. They have not been sentenced to 41 years in prison, perhaps they should.

²⁰ An article about the clinic can be found at: health.spectator.co.uk/the-case-for-prescription-heroin

Apologists for needle supply and exchange schemes argue that they are doing no more than the doctor who supplies contraceptives to sexually active under-age girls. That they are merely protecting the customer from his or her foolishness rather than promoting drug abuse. This is a false analogy.

Sexual intercourse can and does take place without contraception but the needle is an essential piece of equipment for intravenous drug use. Put a sexually promiscuous teenager on the pill and you protect her against pregnancy - give a drug abuser needles and there is no way of knowing how many others may use these same needles. Some rational, intelligent drug abusers will take advantage of an unlimited supply of sterile needles to practise safe techniques but how many drug abusers are rational and intelligent?

Where will this policy lead us? Is it logical to distribute needles freely but severely restrict what is injected through them? Why not make heroin freely available also, the argument will run, and then there is an end to the muggings and burglaries, the attacks on doctors surgeries and chemists shops. No need to share supplies, or equipment and no risk of HIV or hepatitis-B transmission when there are needles and heroin for all comers. The state opium parlour is just around the corner. Is this the society we want?

AIDS is a fearful problem but panic measures are no answer. Heroin abuse is also a fearful problem and we are mad to encourage it by allowing the number of hypodermic needles in circulation to proliferate. The government should think again (McKee, 1988:3).

Given the strength of this editorial which, one might assume, represents one side of a debate, it is easy to see how much more difficult it would have been to argue for heroin to be made available on the NHS. For people who were trapped in the world of drug addiction however, the new harm reduction policies made a real difference.

Annie, a service user who was infected through injecting drug use was very clear about the value of needle exchange and access to free condoms:

If we'd got clean needles we would not have been sharing everybody's needles. You'd maybe have £10 and you're not going to go away and buy condoms, condoms weren't free then. If you had any money it didn't go on condoms or safer sex, it went on your drugs (Annie, 2016).

In the same year that Dr. Greenwood was appointed to her community post (1988), Dr. Welsby, who had been treating injecting drug users in the city, shared some of his learning about the pragmatic approaches and treatment that were needed:

To care for individual IVDA (intravenous drug abusers) an initial realisation must be made that neither the IVDA nor the HIV infection can be managed independently in individual patients. Because there is no evidence that any treatment is uniformly effective for IVDA, prescription for oral substitutes for intravenously abused drugs has been controversial. In the context of HIV, substitute prescription is *not* to treat IVDA but rather to delay the postulated speedier progression to AIDS in those who continue to abuse drugs intravenously (Welsby, 1988:576).

Here, Welsby is making the argument for substitute prescribing for people who are living with HIV. His argument is that although there is no evidence that such prescribing reduces drug dependency, there is an impact on the progression of HIV in those who are infected. The suggestion at the time was that injecting was a high risk practice for progression to AIDS. Presumably this was because there was the risk of introducing infection into the body which was already immune-compromised. I was working with drug users at that time and I can confirm that access to methadone dramatically reduced the use of heroin as a street drug (for a number of years in the mid 1980s there was little heroin available in Edinburgh and addicts travelled to Glasgow to collect their supplies) thus supporting Welsby's theory. It is true that the drug users I know who have survived until now are people who stopped injecting in the 1980s and early 1990s. Interestingly, there has been an increase in injecting behaviour in recent years, at least some of which is associated with the growing popularity of new psychoactive substances such as mephedrone.

By the mid 1990s, there was a better understanding of what might make the difference. Brettle, in his MD thesis, evaluates the impact of harm reduction for injecting drug users:

It would appear that harm reduction measures such as oral opiate substitution therapy and needle exchange when provided in the context of counselling and health education are able to initiate contact with drug users, to maintain that contact and to get across health education and prevention messages. There are preliminary data to show that such measures are safe in that they do not increase drug use or initial drug use, are effective in changing high risk drug behaviour and that oral substitute prescribing such as methadone is protective against acquisition of HIV and may also be protective against progression to AIDS. It seems however that methadone or needles provided without counselling or health education are not effective (Brettle, 1995:161).

Brettle was able to make the connection with health education and counselling support and to recognize that the combination of harm reduction measures and appropriate other interventions made a measurable difference.

I have shown that Edinburgh was dealing with a distinctive HIV problem, unlike that seen in other parts of the UK. Public health responses were quick and, in the main, effective. This has been evidenced in a retrospective study undertaken by Health Protection Scotland. Researchers undertook a review of reviews of needle and syringe exchange programmes (NSP) and concluded that, 'there is sufficient evidence to support the effectiveness of NSP in reducing self-reported injecting risk behaviour' (Palmateer et al., 2008).

2.1.3 Management of drug using patients

Managing and supporting the patients who were HIV-positive injecting drug users brought its own challenges. Brettle clarifies the distinctive problem facing his clinic:

Since the major risk group in Lothian affected by HIV/AIDS are drug users, caring for such patients introduces a number of problems, not faced by other AIDS units in the UK. One of the major problems for a health service is that drug users typically have a crisis type life style with little planning other than for the next supply of drugs. On average heroin drug users require 3-4 doses per day and therefore their horizons are often limited to the next 24 hours. They are not particularly health conscious as demonstrated by their overwhelming addiction and injection drug use which is demonstrably a dangerous life choice. Lastly they have a tendency for a high default rate in terms of the health care system probably because the priorities of addiction come before all else (Brettle, 1995:189).

He goes on to describe some of the management problems that arise:

The characteristics of drug use itself are also important to bear in mind since it is an illegal activity often associated with violence and unpredictable behaviour. The accompanying aggression is often as a consequence of excess (e.g. Alcohol/opiates) or a lack of drugs (e.g. Opiates or benzodiazepines). [...] Since many individuals come from socio-economically deprived areas there is an associated lack of support in the community which puts a greater strain on the hospital services (Brettle, 1995:190).

The clinics then put some pragmatic solutions in place:

For outpatients the clinics have been stratified for chaotic and non-chaotic days as well as offering both drug and medical services at the

same site. In addition higher staffing levels are required to contain and cope with the problems of this difficult population which stretch from 'bad behaviour' to violent aggression and rank psychosis (Brettle, 1995:191).

There were also serious problems when these patients were admitted to the in-patient wards:

Over a 12-month period (from August 1992) the busiest ward for HIV experienced 22 reported security incidents. These consisted of two physical assaults on staff members by patients, one incident of self harm (slashed wrists) by a patient, 11 episodes of verbal aggression towards staff threatening physical assault, 5 episodes of serious self medication requiring medical attention, one episode of theft of a patient's valuables, one episode of a fire alarm being set off by a patient's children and one episode of theft of ward equipment (later returned after lengthy discussions) (Brettle, 1995:193).

Security incidents were also recorded in the outpatient department where 'the peak of incidents [...] occurred in 1989 when there were 40 security incidents or 3.3 events per month' (Brettle, 1995:193).

The impact of managing patient behaviour was discussed by some of the clinicians I interviewed. They all spoke about the flexible boundaries that they put into place in order to ensure the best possible attendance at clinic appointments. In mainstream clinics, late attendance would result in a cancelled appointment. In HIV clinics late attendance was not worthy of comment. The priority was to ensure that patients were seen, and seen on a regular basis. Dr. Dan Clutterbuck, consultant at Chalmers Sexual Health Clinic, spoke about the positive impact on life expectancy of the approach taken by the HIV clinics:

Just when you see the attrition rate as it is and what's happened, you realise it would have happened to the same people a lot sooner, and probably to a lot more if there wasn't that option of being seen immediately in clinic; seen by the people who know you, completely turning a blind eye to your borderline behaviours, accepting behaviour that would not be accepted anywhere else in any other sector, and then putting you into [Waverley Care] Milestone for four weeks without turning a hair. There's a lot of people fall into that group that would be dead. You wouldn't have got through the door in the first place and you would have been dead the next day. There's loads of people like that. And often it's not their HIV that would have killed them (Clutterbuck, 2015).

Welsby commented on the humanity that was shown by staff in the clinics: ‘It’s quite interesting that some of the nurses, I’m thinking of one in particular, almost mothered them’ (Welsby, 2015). This comment connects for me with Brettle’s thinking (above) about a lack of community support for the cohort of people who were most difficult to treat. Waverley Care Milestone (described in detail at 2.7) was a custom built hospice which made considerable efforts to create a sense of community and a place of safety for its regular service users. Section 4.1.1 attests to its success in that venture. For many of the regular Milestone residents, clinical staff and other professionals were the only people in their lives who treated them with kindness and some dignity. The relationships that were formed were very important; people found that the staff cared, that they remembered their names and their situations, and that they wanted to make a difference. Funerals were often attended by clinic staff and by clinicians; these were patients with whom strong bonds were formed.

2.2 The impact on gay men

Another side of Edinburgh’s emerging HIV situation was the impact on men who have sex with men. In the early 1980s, in common with other large European cities, it was becoming apparent that some gay men in Edinburgh were beginning to show signs of the infection that was eventually named HIV. Nigel Cook was involved with Scottish Homosexual Rights Group (SHRG), a group of activists whose focus had been on change to the law and a move towards equality. They began to see symptoms of a new disease that people in the United States were talking about:

Initially it was something that was happening somewhere else, especially in America, and there were all these stories - the gay plague - and much later we discovered it wasn’t the gay plague. People had heard about it, people had visited the United States, and come across it.²¹ I guess the issue was that nobody knew where it had come from. Nobody knew really how it spread. There were all these stories about undertakers in America refusing to do funerals because there was such a big scare. So over here SHRG [Scottish Homosexual Rights Group] was a campaigning organisation, and there had been some success in terms of law reform in the 70s, and the big concern [was] that there would be some kind of backlash, because they’d say well we’ve been nice to these gay people and now look what they’re bringing us. Is it only gay people or could it spread? That was

²¹ For a good overview of the evolution of understanding in the United States see: Shilts, Randy. 1987 *And the Band Played On*.

probably before we were aware that people here had HIV, although it's quite clear from the time immediately after that there were people who were HIV, but they didn't know they had HIV (Cook, 2016).

Dr. Gordon Scott spoke about the earliest attempts at monitoring and the vigilance that was necessary as he and his colleagues were alert to the possibility of infected men presenting at their clinic. He described the first case that was diagnosed in the sexual health clinic in 1983:

I had to sit some exams to be able to progress my career so I went off to do general medicine in the Royal Infirmary with a view to getting my MRCP, which would allow me to come back as a consultant. So I wasn't actually in the unit during that time, but I was just a few hundred yards away, so I was still in touch. I remember Sandy [McMillan] discussing this case with me. It was all based on the symptoms that this guy had. 'What do you think, do you think it is?' 'Sounds like it from everything we know.' It was a really scary time then. You can imagine for the patient it was particularly scary because he knew if it was, what his likely outcome was (Scott, 2016).

Nigel Cook gave an insight into some of the thinking that was being shared within the gay community at that time. SHRG published a monthly newsletter which gave information and advice to gay men as it became available:

One of the other interesting things at that time was that SHRG campaigned for people not to be tested, because back then there were questions starting to appear on insurance papers saying have you ever had a test. The mere fact that you'd taken a test irrespective of the result immediately marked the person as being questionable (as the insurance companies saw it). I think that changed later on and it was the result of the test that was important. Because there was so much lack of knowledge about what was going on, people were just starting to get so careful.

I think there was a sense back then in the gay community that they didn't feel involved, didn't feel it was going to come to them. One of the words that was floating around at the time was ignorance, and that's another part of the message. Because alongside saying don't get tested, we were nevertheless putting out messages about being safe. We were encouraging condom use. It was before the days when you picked them up for free which helped people to use them. There was a feeling that the people who went to the pubs and the discos didn't really see it as something to worry about. It was still seen to be something that happened somewhere else. As long as you didn't go to America, you weren't going to get it. But you might meet someone who'd met someone who'd met someone ... (Cook, 2016).

Michael spoke about knowing that he was probably HIV-positive but choosing not to test for a few years:

I think that was '88, '89 but I don't think I got tested for maybe another couple of years and I think only at that point because my partner was becoming terminal and we shared a flat, and at that point there was no succession rights for same sex couples. I had to apply for a house in my own name so I needed the diagnosis, so I think it was about '90. At that point there was no treatment so I knew my status, I think I knew my status, so what was the point in getting the test. I think it was only because of the housing application that we needed a definite diagnosis (Michael, 2015).

His narrative resonates with my own experience. I was working with homeless people in the late 1980s and a number of them were injecting drug users and/or rent boys who were likely to have contracted HIV. However, they were also people who were struggling to deal with day-to-day living and the burden of an HIV diagnosis at a time when there was nothing to be done, seemed an unnecessary additional complication. On the whole we encouraged people to leave testing until they began to experience health problems. We did, however, encourage condom use and directed people to needle exchange resources.

2.3 Community responses

The earliest community based initiatives came from within the gay community and from the churches. The swift response from gay men is not surprising: they were part of a highly affected community and were directly affected both locally and internationally. There were examples of community engagement from the United States and some of those influenced the initiatives which were undertaken in Edinburgh, as will be seen at 2.3.1 and 2.6. It is perhaps more surprising that the churches became heavily involved in support services, particularly as at the same time there were unhelpful messages being shared by church leaders. I would like first to address the question of the church based initiatives before I move on to consider the other ways that the churches were making an impact.

2.3.1. Positive Help

Helen Mein was married to a priest within the Scottish Episcopal Church and became involved in HIV work at an early stage. She set up an organisation

called Positive Help, which offered practical support to people living with HIV. Here she describes the factors that influenced her initiative:

Early in 1987 on the religious programme on a Sunday morning, I heard the Bishop of San Francisco being interviewed about it dawning on them about HIV/AIDS and the determination of that Diocese to do something about it. And he spoke so inspirationally, and of course Richard [Holloway, then Bishop of Edinburgh] came with the HIV/AIDS message quite high.²² One of the first things he did was to call a meeting of all his clergy to talk about it, to raise awareness with them. So I guess I was attuned to taking this on board. My husband was on sabbatical in the United States and so I made contact with the Bishop of San Francisco and he gave us a contact, a guy who was like an archdeacon. We met this guy, quite a senior cleric, as arranged. We had a moderately bland conversation for about 20 minutes and then the alarm on his watch went off. And he said, 'Sorry I have to take my medication now.' So he took his pill, and we didn't blink, blanch or anything, so obviously we passed the test (Mein, 2016).

This narrative from Mein is a good reminder of the prejudice, and assumptions about prejudice, that were the norm for people who were diagnosed in the 1980s. People became accustomed to negative responses to disclosure of their HIV status. For instance, Annie described feeling '[L]ike a leper. You were scared to tell people because of their reaction. Because they were frightened'. My experience resonates with that described above; people would test out whether or not one was to be trusted and would only go ahead with any significant disclosure if the response they experienced was positive.

Mein then went on to describe how she was invited to visit various projects and to gather sufficient knowledge to inform her planning:

He [the Anglican Bishop of San Francisco] opened up and said we should go and see this organisation and that organisation. We spent the next few days visiting those places. One of the most famous was a place that had buddying and practical help and all sorts of other support all under the one umbrella.

That service formed the blueprint for the agency that Mein set up when she returned to Edinburgh. She recognized the value of practical support and saw that there was a clear gap which a service that relied on volunteers would be able to bridge:

²² Bishop Holloway had returned to Scotland in 1986 from Boston where he had seen the emergence of the illness that later became identified as HIV.

The first tranche of volunteers all came from a church background - Quaker, Catholic, lots of Piskies [Episcopalians], and Church of Scotland. Positive Help gave no indication, and it went out of its way not to give any indication of its antecedents, and its formative bit from the Piskie church. The first six months we were under the Social Responsibility Committee of the Diocese. As soon as we knew we had longer term funding then we went independent with a constitution (Mein, 2016).

This service is an excellent example of a local initiative that depended on good connections with local churches and a structure that supported volunteers to work in a safe and reliable way. Mein had experience of working within the voluntary sector and put into place clear guidelines, regular supervision and ongoing volunteer support. This ensured that the service was run on professional lines and that there were good boundaries in place. Interestingly, one of the firm rules was that volunteers would never initiate 'God talk'. If service users asked about their faith they were allowed to answer, but there was a strong emphasis on meeting people where they were and not being perceived in any way as an agency that might attempt to convert people. Positive Help is one of only two voluntary sector HIV services in Edinburgh that still exists; the other is Waverley Care.

2.3.2 SAFE

Positive Help was not the only agency to come out of a church stable. Support on Addiction for Families in Edinburgh (SAFE) was started by families living on the Muirhouse estate in north Edinburgh. With the help of a local Roman Catholic Priest, Father Tom Williams, they were able to establish a furniture recycling scheme which supported young people to find a way back into independent living. The Muirhouse community was one that was seriously impacted by HIV; it was an area where many drug users had been housed and a high percentage of local families were affected. As the extent of the HIV problem became apparent, a befriending service was started within SAFE alongside occupational placements and creative writing schemes (Cullen, 1999, 11-12).

2.3.3 Church of Scotland services

Meanwhile the Church of Scotland was also involved. Its drug counselling service at Simpson House began to see people who were directly affected by HIV and

the counsellors there developed a particular expertise in working with newly diagnosed people. Perhaps the most remarkable initiative was taken by the Women's Guild of the Church of Scotland, which celebrated its centenary in 1988 and decided to mark that by fundraising for a project that would celebrate 'women helping women'. The decision was made, in conjunction with the Board of Social Responsibility of the church, to establish a project that would offer support and HIV education to street prostitutes. The Centenary Project opened in 1991. In its first leaflet it described the service as offering: 'clinic, drop-in, workshops, confidential support, advocacy and non-judgmental counselling on housing, legal and welfare rights, drugs, alcohol, sexual abuse and violence' (Centenary Project, 1991). This ambitious list of aims was supported by Lothian Health in the form of outreach clinic support from the sexual health services.

Gordon Scott was involved:

They got 36 Henderson Street and set that up as a drop in clinic which was open every night. And then on a Thursday night I and one of the nurses used to go down there and do clinic. That was an eye opener. The first patient we saw was sixteen, had been sexually abused, had such low self esteem that she was just incapable of protecting herself from anything. It was really sickening actually to see the vulnerability. There weren't a huge number of drug users though. That's one of my recollections. The whole premise for my involvement was, let's prevent HIV infected drug users from infecting the population. It rapidly became clear that wasn't what you needed to do; what you needed to do was help incredibly vulnerable and abused women, which was very difficult to do. But sexual health needs were often the last thing that needed addressed (Scott, 2016).

I worked at Centenary Project for about 18 months from early 1992. By that time, there was an established nightly drop-in service running from 8pm - 1am. Staff went out onto the streets to meet the working women and to offer them condoms and information about the service. The intention was to engage with women at night and then to encourage them to meet with staff during the day in order to follow up on identified support needs. It would be fair to say that there was relatively little HIV-related day time engagement, and few of the women openly disclosed their HIV status. Most of the support work I engaged in was to do with domestic violence and child support. We did, however, see a good number of women over the course of the week and had a lot of discussions about sexual health and condom use.

2.3.4 Harm reduction and the churches

The homelessness project I worked with in the mid 1980s, The Ark, was run by a local church, Old St Paul's, a city centre congregation within the Scottish Episcopal Church. We had condoms openly available and encouraged people to take them. At one stage, a more conservative church project used our premises on a temporary basis. Our project ran from 6am to 1pm; they used the premises in the evenings. The other church project was not happy to distribute condoms and became concerned about how to manage what they perceived as a problem. Their solution was to put the condoms away during their time in the premises and to tell people who asked that they could access them in the mornings when the project I managed was open. There was no understanding that the condoms would probably have been used that evening and tomorrow morning was almost certainly too late.

The responses of the churches in Scotland to the promotion of condom use were mixed. The Scottish Episcopal Church, as evidenced above, took a pragmatic, harm reduction approach. There was never a question raised about the supply of condoms at The Ark. Helen Coyle's research shows that there was more reluctance within the other mainstream denominations (Coyle, 2008:239). We can also see that although there was a desire to offer support and care to people in need, there was a real ambivalence about condom use. This is seen in the following quotation which includes input from Father Tom, the priest from Muirhouse who was involved with SAFE:

For some, Edinburgh's HIV problem had made the use of condoms a 'regrettable necessity'. These were the words of a local Catholic priest, Father Tom Williams, who was the AIDS Liaison Officer appointed to an HIV/AIDS action team to promote education about the virus. In a press statement, Williams claimed that, while the Christian ideal was that sex should take place only within marriage, it had to be accepted that the behaviour of many people did not live up to that ideal. Therefore, his view was that, if someone was going to engage in sex, then he would say 'Take Care' and use a condom. An Official Spokesman for the Catholic Church stated that Father Williams' message was acceptable because he was speaking to 'non-church people'. Meanwhile, the Church of Scotland remained of the view that they would take every opportunity to emphasise the teachings of chastity before marriage and fidelity within marriage. They firmly believed that non-adherence to these teachings could increase the risk of infection. Similarly, the Free Church of Scotland expressed concern that HIV/AIDS educational material was damaging in that it assumed immorality as the norm (Coyle, 2008:239).

The 'official' church response that Father Tom was talking to non-church people and that it was therefore acceptable to mention condoms is curious. Clearly, the words of a Catholic priest will be heard by a range of people. There may have been assumptions about the moral choices that were being made by members of the Catholic church. I would dare to suggest that any such assumptions were erroneous.

The Church of Scotland was equally conflicted between its words and its actions. The Board of Social Responsibility ran projects working with people who lived with HIV. The rationale for the Centenary Project was to implement harm reduction policies and yet in its report to the General Assembly in 1992 the Board took a very conservative line:

The Church proclaims the healing love of God in Christ, and it is the responsibility of the Board to embody this love among people affected by the HIV infection. Without being doctrinaire or judgmental the Church must take every opportunity to emphasise its teaching of chastity before marriage and fidelity within marriage. Non adherence to this teaching rapidly increases the risk of infection and all its serious ensuing consequences (Northcott, 1993:37).

This statement resonates with global initiatives that were being promoted at the time, especially in some African countries. The ABC campaign (abstain, be faithful or use a condom) was very widely used, with a primary emphasis on A and B, making C almost an 'if all else fails' alternative. Discussing HIV prevention from the perspective of abstinence and fidelity made it much easier for church leaders to become involved in discussion about the virus within their communities. The ABC model has been criticised, most importantly because it fails to take account of gender politics and the inability of girls and women in many countries to negotiate the kind of sex they want (Murphy, 2006: 379). The General Assembly statement takes no account of the fact that fidelity on the part of one partner within a marriage is no guarantee of fidelity on the part of the other. I recently met a woman who had been married for more than forty years and had just tested HIV-positive. She had never had another sexual partner and had only just discovered that her husband had been unfaithful to her throughout their marriage.

2.4 Wider faith community engagement

In 1993, an ecumenical conference was held in Glasgow ‘witness[ing] to the significant desire of Christians in Scotland to respond to the epidemic in positive and caring ways’ (Northcott, 1993:5). The conference, entitled ‘Theology in Transformation’ emerged out of the work of the Strathclyde Inter-Church AIDS Project. Although the work of that project was focused on the West coast of Scotland, there are some useful and significant findings within the conference papers.

2.4.1 Churches and sexual health education

The Strathclyde Inter-Church Project gathered information from health workers in their area. They discovered that there was a serious problem with the dissemination of information:

[V]ery considerable obstacles to effective sex education amongst young people in the West of Scotland have been erected by the Roman Catholic Church through their control of schools. Leaflets, pamphlets, videos or curricular materials which promote the use of contraception are suppressed in Catholic schools in the Strathclyde Region. This means that a principal mechanism for preventing the spread of the disease is restricted by the influence of the Church in the West of Scotland (Northcott, 1993:8).

The suppression of information was not restricted to Catholic schools in the West of Scotland. In 1993 a schools’ resource was put together by Father Tom Williams (the priest who was involved with SAFE (2.3.1.2) and who made the somewhat surprising statement on condom use quoted at 2.3.2) in collaboration with a local community worker, Rhona Hutchison. That resource became the subject of an enquiry by The Congregation for the Doctrine of the Faith and the Diocesan bishop was given no option but to demand the withdrawal and destruction of the packs. The full story is shared by Kenneth Owens, writing in *Catholic Ethicists on HIV/AIDS Prevention* where he attempts to untangle why what seems like an obvious initiative was received so badly. He concludes that the resource pack contained insufficient explanation of the thinking behind certain decisions, for example to include details about secular sources of information, and was therefore seen as having the potential to undermine the position of the Catholic Church. Owens, in his reflection on the harsh response to the resource, says:

One of the saddest aspects of the silencing and withdrawal of this resource pack was that the voices of those living and working with individuals affected with HIV/AIDS were not listened to or valued. The Catholic community's response to the HIV/AIDS crisis was impoverished through this experience... Neo-orthodoxy was prized above all else (Owens, 2000 :167).

Northcott draws to our attention the fact that worldwide fifty percent of infections were in the fifteen to twenty-five age group and that the World Health Organisation has shown that open and honest sex education at an early age leads to delayed first sexual activity (Northcott, 1993:9). In other words, young people who are not able to access information about sex and sexual health are more likely to become sexually active at an early age and, inevitably, more likely to become pregnant or contract a sexually transmitted disease, or both. *Astrid's* story in chapter three is clear evidence of this point. She was a young Roman Catholic woman who described herself as innocent and ignorant. She was pregnant and HIV-positive by the time she was seventeen.

Not all church leaders felt obliged to speak from a position of orthodoxy. Richard Holloway, Bishop of Edinburgh from 1986-2000, spoke from a much more radical position at the interfaith conference. He suggested that:

The AIDS epidemic and the responses to it are a very paradigm of the Gospel. Again we see human extremity met by unconditional love, and it is the medical profession which is the exemplar of grace here (Northcott, 1993: 43).

Holloway recognizes that HIV pushes people towards some kind of limit, whether that be a limit of tolerance or compassion or understanding. Over the years there has been a tendency within the faith communities to separate people into 'innocent' and 'not innocent', (i.e. 'guilty') victims. Firstly, people who are living with HIV are very clear that they do not want to be perceived as victims. Secondly, to suggest that the means by which someone contracted the virus makes them more or less worthy of care and support is deeply offensive. Whatever the route of transmission, be it blood products (as was the case for haemophiliacs), mother to child, injecting drugs or sexual contact, people did not choose to contract the virus. The inclination, within some circles, to be negative about some groups of people who are living with HIV and to be sympathetic to others is not a Christian response. This tendency is perhaps

evidenced by looking at fundraising ventures. The fundraising team at Waverley Care have always found it easier to raise money to support children who are infected and affected by HIV than to raise money to support their parents.

2.5 The emergence of other local support services

I noted above that the SHRG took an active interest from the early 1980s in accessing and disseminating information on the emerging problem. Four members of that group went on to form a separate group with a focus on HIV - Scottish AIDS Monitor. Nigel Cook described its beginnings:

Scottish AIDS Monitor (SAM), I think it was the word monitor that was the clue to what it was about. It wasn't necessarily a campaigning organisation. It was an organisation to check what was going on, to find out information, and then to go and engage with people. I remember very early meetings with the blood transfusion service. They were the first people I think where we thought there was going to be a problem. Gay blood was not accepted. It could have been one of those issues that got exposed and magnified and used to change the flow of acceptance of the gay community (Cook, 2016).

2.6 The NAMES project

In the late 1980s a local man, Alastair Hume, had learned of the NAMES project which was emerging in the United States. It created quilts as a vehicle for HIV awareness and as a tool to remember those who had died. Cleve Jones had been involved with a gay rights march in San Francisco in November 1985. He heard that 1000 San Franciscans had died of AIDS and so he asked everyone on the march to write down the names of their friends and loved ones who had died. At the end of the march the names were taped to the walls of the federal building. Cleve looked at the impact and it struck him that the names looked like a patchwork quilt and so the idea for the NAMES project was born.

A press release from 1992 states the goals of the NAMES project:

- To confront individuals and governments with the urgency and enormity of the AIDS pandemic, and underscore the need for an immediate and compassionate response, by revealing the names and lives behind the statistics.
- to build a powerful, positive, creative symbol of remembrance and hope - the NAMES Project AIDS Memorial Quilt - to link diverse people

worldwide in the shared expression of our common pain, grief and rage in response to the AIDS pandemic

- to encourage donations in every community where the Quilt is displayed, thereby raising the desperately needed funds for people living with HIV/AIDS and their caregivers.

In 1988, the Quilt was nominated for a Nobel prize. Materials used on the panels included, Barbie dolls, buttons, carpet, cremation ashes, credit cards, feather boas, human hair, lace, badges, pearls, photographs, wedding rings, lottery tickets, passport, pillowcase, rubber thongs and running shorts (Names Project, 1992).

In June 1989 Hume set up an Edinburgh panel-making workshop and formed the Names Project UK which continued to be based in Edinburgh. The first exhibition of British panels was in December 1989 at a fundraising exhibition for Milestone House. The British Quilt was officially launched during the Edinburgh festival in 1990 with an exhibition at Waverley Care Solas (Names Project, 1990).

The Names Project (UK) produced an (undated) leaflet describing its purpose:

Making these panels has helped tens of thousands of people to work through their feelings, and on a wider scale the Quilt has helped to promote a compassionate response to the issues surrounding AIDS. It is impossible for visitors to see the personal messages on the panels and not be touched (Names Project (UK), n.d.).

The Scottish Names Project panels are now lodged with the Lothian Health Services Archive at the University of Edinburgh. The other UK panels are currently held by George House Trust in Manchester. Work is being undertaken to find a permanent home for them.

2.7 Waverley Care

In December 1988, the Waverley Care Trust was established. Its stated purpose was 'to promote the welfare of, care for, aid and assist persons residing in

Lothian Region with HIV-related illness and their relatives and dependents' (Waverley Care, 1991, intro.).

The Waverley Care Trust grew out of SAM whose Chair, Derek Ogg, and a committee member, Edward McGough, argued that Edinburgh's HIV-positive population would need a specialist facility which could offer respite and end-of-life care. After many months of negotiation with local communities and a sabotaged start at another site where a fire was started, Milestone House was built in the grounds of the City Hospital, where the Special AIDS Unit of the Health Board was located. Milestone was built as a sixteen-bedded unit following the model of a similarly styled hospice in California. Each bedroom has en-suite facilities and a door that opens directly onto garden area. The unit is surrounded by pine trees and has a distinctly rural feel. Birds, squirrels and foxes are regular visitors. For service users from inner city areas, this was a notable feature, so much so that within a few months of the unit opening the fox had been adopted as a mascot and fox badges had been commissioned. A memorial quilt, designed to remember those who have died at Milestone, has taken on great significance for service users and staff within Waverley Care. Its design is a tree of life and it features a fox for the same reason.

In the enthusiasm to open this new service, the management committee were perhaps a little short-sighted in their planning. Jane Millard who was ordained in 1990 by Richard Holloway as Bishop's chaplain to people living with HIV explains:

When it was newly open, the then director was showing people round and they asked to see the Chapel, hospice Chapel, and I think he was a bit taken aback and said 'We don't have a Chapel' so they asked to see the chaplain and he said 'We don't have a chaplain' and the visitor said 'Who's going to bury your dead?' (Millard, 2012).

The result of this conversation was that the Board of Management very quickly advertised for a part-time chaplain and the place of spiritual care within the agency was established. In those early years, the role was modelled on mainstream hospice chaplaincy, working with people to prepare for the end of their lives, taking funerals and offering bereavement support.

‘Who’s going to bury your dead?’ is a question that has arisen again as a result of the chaplaincy post being made redundant. Service users and peers have asked that question of me. It is not yet clear how that question will be answered.

The early years in Milestone House were years where the focus for staff and service users was on death. Helen Mein, in her role with Positive Help, was acutely aware of this:

We were living with people dying of AIDS. By the time I left Positive Help after 6 years, over 110 of the people we’d helped had died. That’s a helluva lot of deaths. That brings people of faith up against it. It brings everybody up against it. Our punters were going to the edge and coming back. And everybody in the family and everybody geared up to it, and then they came home again. And the children were living with this (Mein, 2016).

Jane Millard contributed to a booklet *The Church is Positive* which was compiled by the Scottish Episcopal Church in 1993. Below is some writing from her *Fragments of the Watch - Reflections and memories from watching and praying alongside those who are dying. 1987-1992*. They give a real flavour of how demanding the ministry was for those who watched and waited with those for whom there was no hope.

‘Will my mummy go to heaven?’

‘What do you think?’

‘My mummy doesn’t believe in heaven.’

‘So what do you think about that?’

‘Oh, heaven is a place. A huge, large, enormous fluffy cloud. They play guitars - no they are like this.’

‘Harps?’

‘Yes, they are like this.’

‘Can mummy play a harp then?’

‘No, silly, God will teach her. I’m going to play the recorder at school, when I’m in the big school.’

The nurse weeps as she prepares your body. I scoop her tears and anoint you with her sorrow and her powerlessness to restore you to health. I touch her with your fingers to anoint her with your understanding.

We talk about it often, you and I. How HIV faces us with a challenge to our professionalism. The doctor can't heal, the nurses can't always soothe away your pain, the cooks can't give you food that you can tolerate, you can't bear the noise of the vacuum cleaner, so the domestics stroke your hair and blether, the chaplain can only hold you and pray.

'All will be well' you said with simple faith, binding us all in patient, exhausted love.

(Scottish Episcopal Church, 1993)

Milestone continues as a Waverley Care service. It is now (2016) a respite and intensive care centre offering residential and outreach support to people living with both HIV and Hepatitis C.

2.7.1 Waverley Care Solas

In 1993, Waverley Care took over managerial responsibility for Solas, a community HIV resource that had opened in 1990. It was based in premises that had been the Gateway Exchange, an arts based community centre in the Abbeymount area of the city which had been opened by Sarah and Jimmy Boyle, specifically to offer support for people who had been through the prison system. Solas (the Gaelic for both solace and light) sought to offer a one-stop shop for people living with HIV in a safe therapeutic environment. Complementary therapies were offered alongside counselling, support and advice (Solas leaflet, n.d.). Solas continued to use the café space set up as part of the Gateway Exchange. The café served several purposes: responding to the need for good nutrition for people living with HIV; providing informal opportunities for peer support; as an exhibition space for the art work that continued to be part of the programme of activities; and as a public café helping to break down the stigma attached to HIV. Individual and group support for children living with and affected by HIV was available from the start and this was the first dedicated service of its kind in the UK. Support included helping parents to tell their children about HIV, dealing with loss and bereavement and helping parents to create memory boxes for their children. Services at Solas developed in direct response to service user need. For example, a group of gay men was regularly

using the centre and a supportive group was formed, Juice, which met regularly both to offer information and support and to create opportunities to socialise. The Juice group was able to offer service user feedback and input on safer sex materials as they were developed, ensuring that the materials were as relevant as possible for their target audiences. A women's group, Isis, also emerged in response to the number of women who were living with HIV in Edinburgh. There was a large theatre space at Solas which hosted events such as funeral workshops (including painting cardboard coffins), art events and workshops that created material for public exhibitions to raise awareness about HIV. Solas hosted the first ever UK exhibition of the Names Project in 1990, with a second exhibition in 1998.

As HIV changed over the decades so did the services at Solas, offering a programme that supported people who were coming to terms with living, not dying, and thinking about what to do next. Solas was the first third sector service to respond to the needs of Africans living with HIV in Scotland, delivering both prevention and support services. The lease of the Abbey Mount premises came to an end in 2007 and this coincided with a decline in the use of the café and much reduced funding for complementary therapies. It was decided to bring together community services with the fundraising and head office functions of Waverley Care and the remaining community based services that were offered from Solas, including information and advocacy, children and families support, skills and employability and health promotion were moved in 2007 to premises in Mansfield Place, Edinburgh.²³

2.7.2 Spiritual care within Waverley Care

There was an internal review of the Milestone House Chaplaincy service in 1995. Its purpose was 'To determine areas of consolidation and development in the light of users' and colleagues' experience of chaplaincy, and available resources' (Review of Chaplaincy in Milestone House, 1995). At that time there were two part-time chaplains. Jane Millard was a priest within the Scottish Episcopal Church and Ron Dick was a minister within the Church of Scotland. Both had church-based responsibilities alongside their work at Milestone House.

²³ Facts verified by Martha Baillie, manager of Solas

The conclusion of that review shows that the service was beginning to develop and to extend its reach:

Chaplaincy is seen as an integral, valued and often distinctive contribution to the life of Milestone House. The chaplaincy will continue to focus on encouraging all in Milestone to develop their own spirituality, and to provide opportunity and resource to explore belief in its widest sense and faith in its broadest sense. The expressed need and preference for greater availability of the Chaplains indicates that the focus for their work remains in Milestone House. The Chaplains' role is understood to cover a wide remit, and is not restricted to bereavement care²⁴ (Review of Chaplaincy in Milestone House, 1995).

The report includes verbatim comments from members of staff. A number are reproduced here in order to give an indication of the way the service was perceived and experienced.

'You are available'

'You sit about talking to people, drinking coffee'

'We'd notice if you weren't here - don't you dare slope off to Solas'

'The chaplains love the people'

'We'd only notice what you really do if you weren't here to do it.

Perhaps that's what's so good - chaplaincy doesn't intrude, it's very powerful - this quiet presence.'

'Who looks after you two? I suppose you will say God...'

I am struck, in particular by the comment that 'We'd only notice what you really do if you weren't here to do it'. The essence of good chaplaincy is that it functions unobtrusively and is most recognised by its absence rather than its presence.

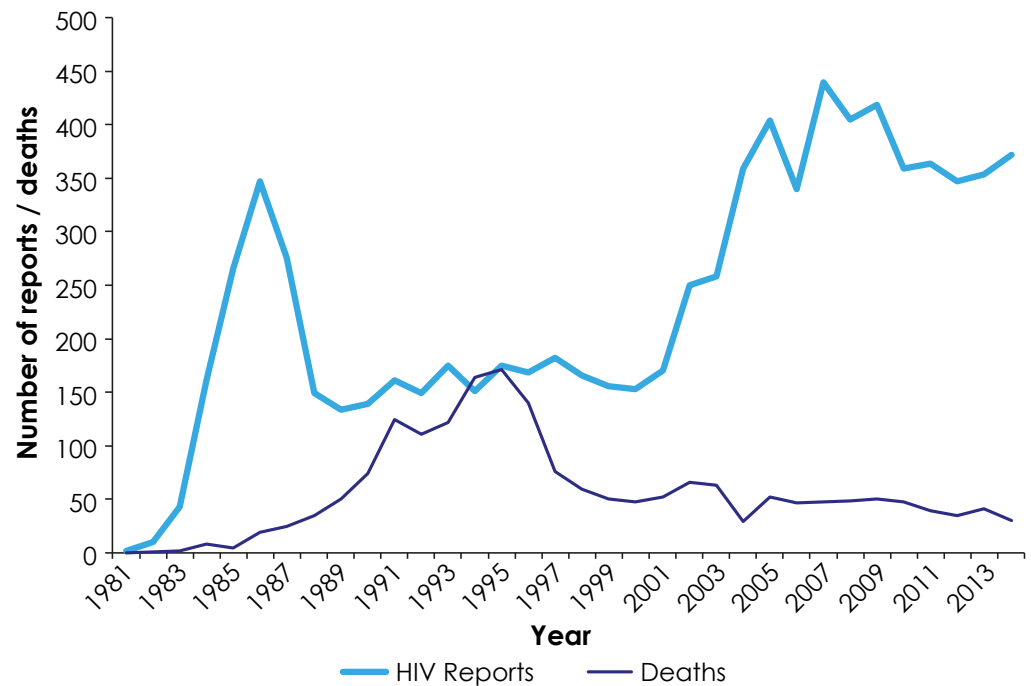
By the beginning of the twenty first century, treatments for people living with HIV had been introduced and were having good results. The number of deaths had reduced (see figure 1) and the focus for health providers was shifting towards ensuring the adequate provision of treatment. The hospice had been jointly funded by the City of Edinburgh Social Work Department and Lothian

²⁴ Quoted verbatim

Health Board. In 2001, the Health Board made a decision to withdraw its funding and the shape and function of the service changed dramatically.

Figure 1.

HIV Reports and Deaths among HIV infected individuals; Scotland (to 31 December 2014).



Cause of death may not be directly attributable to the individual's HIV status.

Source: Health Protection Scotland.

The chaplaincy service adapted in response to the changing climate. A poster presentation was offered at an International HIV Conference in Milan in 2003. It illustrated the development of the service from one that was based within an institution to a model more akin to parish ministry. The poster is reproduced on the following page.



Waverley Care

A MODEL FOR SPIRITUAL WORK WITH PEOPLE LIVING WITH HIV

Spiritual care for people living with HIV has moved from an institutional model, based in a hospice, to one which is rooted within the community.

This has allowed access to funding from a range of churches, more ownership within congregations, more holistic pastoral care and a legitimate remit to address stigma and discrimination within the wider community.

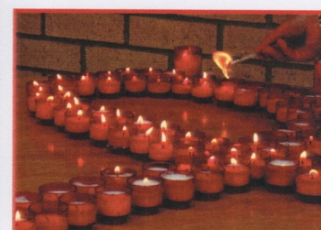
DESCRIPTION

Historically, service users had regular hospice admissions which enabled the chaplains to build and sustain long term relationships. The main focus was death and dying. Newer models of holistic care give fewer residential admissions and therefore require a different approach to pastoral care. The issues to be dealt with are also wider - for many people the need is to address the spiritual aspects of living with HIV rather than to prepare for their own death. This has been achieved by:

- Following up admissions with home visits where there is ongoing work.
- Establishing therapeutic support groups for service users.
- Being available in a variety of settings.
- Ensuring that service users have direct access to chaplains as well as offering support and educational resources to the wider faith community.

CONCLUSIONS

As the issues for people living with HIV have changed, their spiritual needs have also changed. Spiritual care within this new context requires constant review and flexibility - but brings many rewards to carers and service users.



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The poster presentation shows how the spiritual care service was able to respond quickly and appropriately to changing needs within the service user population. That responsiveness continued to be a distinguishing feature while there was a dedicated spiritual care role. Waverley Care employed a chaplain (under various job titles, as described in chapter one) until April 2016 when a decision was made to make the role redundant. It is not yet clear how spiritual care will be offered to this client group in the future, although the need for such care has been shown here and will be discussed in later chapters.

2.8 A sexually transmitted disease

By the early 1990s it was clear that HIV had primarily become a sexually transmitted infection and that the focus for prevention work needed to be on sexual health and condom use. Our understanding of the efficiency of sexual transmission is helped by an editorial in the *Postgraduate Medical Journal*. Written in 1997 by Philip Welsby it is a ‘tongue in cheek’ view from the perspective of the HIV virus:

We are primarily a Sexually Transmitted Disease (STD) which has given us three main advantages. Firstly, as delicate organisms, we have avoided much wastage by discovering a route of transmission that avoids harsh external environments. Secondly, there is a lot of human sexual activity going on. There is one new attendance at STD clinics for every 56 members of the UK population above the age of 15 and below retirement age each year. Of course not all STD clinic attenders have an STD, but still that is an awful lot of humans who think they might have been at risk of STDs. Thirdly, human semen is immunosuppressive (presumably to protect the foreign protein spermatozoa from being killed by female immune reactions), presenting a highly satisfactory vehicle in which to transport an infection (Welsby, 1997:609).

2.8.1 Public health responses

Helen Coyle describes the public health campaigns that were initiated in response to the fears that had been generated:

From 1991, the LHB [Lothian Health Board] and the LRC [Lothian Regional Council] had dedicated considerable effort and resources into furthering the ‘Take Care’ campaign, emphasising the risks from heterosexual transmission. They reinforced the ‘safe sex’ message using a range of media outlets, which included adverts in newspapers, on the radio, in the cinema, inside and outside buses and even at football matches and pop concerts. Some efforts received worldwide recognition, such as the cinema advert, entitled ‘Use a Rubber’, which won an award for its design.

In addition, a second mail drop to every household in Lothian occurred in December 1991 as an 'Update' to keep Lothian's HIV/AIDS problem prominent in the minds of its citizens. This included information on the estimated incidence of HIV infection through heterosexual transmission amongst men and women in Lothian (1 in 100 men and 1 in 250 women were said to be HIV-positive). Advice was also given on condom use and emphasis placed upon the importance of having sexual relations only with a faithful partner. Efforts to boost the 'Take Care' campaign occurred again in 1994 when a total of £50,000 was spent on a new campaign message, which now highlighted two possible ways of taking care, by using condoms or simply saying 'no'. The rationale behind the latter message was the belief that many women, if empowered, would say 'no' to casual sex. An evaluation survey of the 'Take Care' campaign in 1993 had revealed that many saw it merely as a campaign to promote the use of condoms as a means of preventing HIV/AIDS. Other 'Take Care' choices, such as choosing to have a relationship without sexual intercourse, were not identified by any respondents who took part in the survey. Therefore, greater emphasis was placed on the phrase 'Taking Care', with messages such as 'Have you worked out what taking care means for you?' and 'Are you still taking care?'. These messages were promoted to encourage personal reflection within the context of active sexual engagement and, as with previous messages, they were advertised using a range of media outlets, which included a message on 130 Lothian double decker buses (Coyle, 2008: 237-238).

This local public information initiative followed a national response. In 1986, Norman Fowler was Secretary of State for Health in Margaret Thatcher's Government. Despite some resistance from his colleagues, Fowler was determined to treat HIV as a public health issue and as early as March and April 1986 he ensured that newspaper advertisements offering safer sex advice were published and a leaflet was delivered to every UK household in January 1987 (Fowler, 2014:5&17).

Throughout the 1980s and early 1990s knowledge increased and the responses to the epidemic began to be tailored to the situation on the ground. It became increasingly clear that local circumstances were key to making those responses appropriate and proportionate. Coyle clarifies this:

On the first World AIDS Day, 1 December 1988, a number of public events took place [in Edinburgh]. These included a banner displayed at the top of the Mound overlooking the city centre, with the words 'AIDS Concerns Us All'. Pink cards and car stickers were distributed throughout Edinburgh and the message 'Take Care' was exhibited on all Lothian Regional Transport buses. In addition, the LRC included information on HIV/AIDS in the form of a small 'Take Care' card sent to all of its 50,000 employees.

A 'Ready Guide' was also produced which listed all the services and facilities in Lothian for people with HIV and AIDS (Coyle, 2008:218).

World AIDS Day celebrations continue to be an important marker for the community. For a number of years there was a march through the centre of the city, culminating in a candle lighting and naming event in Princes Street Gardens. In 2003, a decision was made to move the event indoors (1 December in Edinburgh can be a very cold and miserable day) and to seek to find a balance between remembering those who had died and celebrating the advances that had been made in treatment and prevention. St. John's Episcopal Church on Princes Street became the venue for the annual event which attracted around two hundred people. I hosted it every year until 2015. The World AIDS Day event was tagged 'celebrate, reflect, remember' and the intention was to ensure that each of those elements was addressed. There was time dedicated to naming those who had died, time for speakers from various perspectives and time for musical or theatrical input to balance the event. It became a focal point during the year, especially for bereaved families who knew that they could safely name their loved one and meet with other people whom they had encountered at Milestone. The Milestone quilt formed the backdrop for the event; it is in the form of a tree of life on which names have been embroidered. It is an ongoing project.

2.9 Summing up

The HIV picture in Edinburgh has changed significantly since the first diagnosis in 1993. At that time there was little understanding of the nature of the virus, no way of managing the impact of the virus on the immune system and no message of hope for those who were diagnosed. The infected community included a significant number of injecting drug users and there was real fear about onward transmission into the heterosexual community. The people tasked with finding an immediate response introduced radical harm reduction policies that, with the benefit of hindsight, can be seen to have been highly effective.

The churches were at the forefront of community based initiatives and without the volunteer hours offered by individual church members, the daily lives of people who were living with HIV would undoubtedly have been more

difficult. Those in positions of authority within the two largest churches in Scotland were responsible for blocking sexual health education messages that might have made a difference for young (and not so young) people within the community. We will never know what impact the prioritising of discourse about perceived sexual sin, an emphasis on abstinence ('just say no') and faithfulness, and a reluctance to focus on teaching that God's mercy and love do not discriminate, has had on the spread of the virus. Abstinence and fidelity are clearly helpful tools in the fight against HIV. However, they rely on pre-conditions, the first of which is the assumption that people embarking on sexual relationships have the skills and confidence to negotiate sexual choices. Secondly, these messages assume that each partner in a relationship can rely on the other to be faithful. These challenges are discussed at 2.3.4. The harm reduction approaches which were adopted in Edinburgh, and have been proved effective, offer a pragmatic response to a serious problem. It is a matter of sadness and concern that the two largest churches in Scotland were not able to encompass those approaches.

I have explored the distinctive Edinburgh HIV story and shown how the emerging epidemic was of a different nature to that which was being experienced in other parts of the United Kingdom. I have shown that local responses were important and well tailored to meet the needs of the community they served. Chapters three and four give voice to people living with and directly affected by HIV and offer us an opportunity to explore the salient issues in depth.

Chapter 3: Diagnosis, Stigma and Mortality

3.1 Introduction

This chapter and the following one contain much of the research material gathered during the course of this project. In this chapter I will initially focus on the impact of an HIV diagnosis on both patients and clinicians. I describe the situation that existed before treatments were available and then consider the implications of accurate testing. I will show that the focus for prevention and treatment was biased towards injecting drug users and explore the reasons for that decision.

In line with the IPA approach to recording oral history, I have reproduced a significant amount of transcribed material. One aim of this thesis has been to give a voice to people who would otherwise be voiceless. My interest in sharing these stories is in recording oral histories, the memories of those who were there at the time and lived through the experiences. Working with respondents whom I already knew gives the research material depth and personal meaning. I would suggest that HIV has been an agent for change in each of these lives; it has also been an agent for change in the field of substance abuse, where harm reduction measures are now the norm. Looking at the historic records, for example the editorial in *Edinburgh Medicine* which I reproduced at 2.1.2, it seems unlikely that such measures would have been so readily accepted without the threat of HIV to influence the agenda.

The transcript material that I have used within this chapter is from interviews conducted in 2015 and early 2016. For ease of reading, I have chosen not to reference and date each extract, but have referenced the first time I have used the words of each participant in any section. Biographical information on the participants and detail of interview dates can be found in appendix one. Pseudonyms have been chosen by some participants and they are written in italics throughout.

3.2 The earliest indications of a problem

HIV is a blood-borne virus which is currently diagnosed by blood testing; accurate blood testing became available in Scotland in 1985. Dr. Gordon Scott, consultant physician in sexual health, was one of the clinicians who saw the earliest presentations of HIV in Edinburgh. He describes the situation prior to the availability of blood testing:

Guys would come in and they would say I've just discovered that someone I had sex with a few years ago has died of AIDS, has got AIDS, what's gonna happen to me. Well that was a nightmare because, well we maybe just knew there was a virus, HTLV111 was discovered around Spring '84, but there still wasn't a test. So all we could ever do, if they didn't have any specific symptoms, all we could ever do was feel for lymph nodes. We always used to feel for lymph nodes at the back of their neck. It was good news if you didn't find them. But if you did, there was nothing you could do. So it was a kind of really bizarre time when people would come in looking for reassurance and you actually really couldn't give that. And then we got the odd guy who would be unwell. And as I say there was really nothing we could do (Scott, 2016).

Early in 1985 a reliable blood test became available and it was possible to give an accurate diagnosis to people who might have contracted the virus. In 2016, there is a range of testing options available including same day testing, postal testing and instant saliva tests. In the 1980s the tests were more cumbersome and the results often slow to materialise. Scott described the situation from a clinician's perspective:

Towards the end of '84, beginning of '85 a test became available. It wasn't routinely available but the laboratory could do it. It was the most inefficient system known to mankind. You'd take the blood from them, send it up and then two to three weeks later you'd get a phone call. You never knew when you were going to get the phone call. I suspect they probably waited till they had ten or twenty or however many samples, and then did a run and the timing of the run depended on how many samples were getting sent up. But two or three weeks later you'd get a phone call saying 'that one's positive'. You never got a bit of paper. You would call the poor bloke in and say 'I'm sorry but your HTLV 111 test is positive'. 'What happens now?'. 'Erm.. We wait and see'. But all the time them knowing that people are going on to get AIDS and there's no treatment.

In this section of his interview, Dr. Scott helps us to see the scale of the challenge for medical professionals in the very early days of the epidemic. He was working in a branch of medicine that expected to treat and cure all of its patients. Sexual health clinics (known at the time as Genito-Urinary Medicine)

offered diagnosis and treatment with the expectation that the outcome would always be good. HIV was a game changer for people working in that specialty of medicine; it required them to approach the treatment of their patients very differently as they had nothing effective to offer. At this stage, the only other centre making diagnoses in Edinburgh was the clinic treating haemophiliacs, some of whom had received infected transfusions of factor VIII.²⁵ This was a small group of people who continued to be treated by their specialist clinicians.

Dr. Scott described the impact of making a diagnosis:

It was pretty ghastly. You would make a diagnosis. We didn't do CD4 counts to begin with.²⁶ The first thing we used to get were CD4 ratios, CD4/CD8 ratios. And you divided them into less than 0.3 was bad; 0.3 - 0.7 was intermediate and greater than 0.7 was OK. And that very quickly came along as percentages. Anything less than 15 percent wasn't brilliant, which we now equate to [a CD4 count of] round about 200. And then we got the counts but that was actually quite a bit later. We had other tests that we could do that gave you a rough idea of what was going on. A lot of it was, how is your patient. My patient's got pneumonia. My patient's got intractable diarrhoea. You were trying to sort out that problem. But you pretty much knew that you would sort that one out and something else would come along and it would be harder to treat until eventually we'd get CMV retinitis or something really horrible. You knew you were then on the, well we're changing now from active management to preparation for death. That was tricky. There is a point that you know that we're now on a really downward trajectory. Is the patient ready for that?

Dr. Scott was well aware of the prognosis for these patients. He had been researching HIV since 1981 when he began his career in sexual health medicine. He describes how the medical professionals in his clinic began to gather information:

Virtually the same day I started there were these cases in the medical literature of pneumocystis carinii pneumonia and kaposi's sarcoma in gay men in New York and San Francisco. And just after I started we had a journal club and so they asked me to review articles and present them to the rest of the department. So I presented these two papers, one from the *Lancet*, one from the *New England Journal of Medicine*, and we all kind of talked about them and said 'Is it going to come to anything?' and I

²⁵ Factor VIII is a blood-clotting protein

²⁶ CD4 is a glycoprotein found on the surface of immune cells. The standard laboratory test measures the number of CD4 T lymphocytes (CD4 cells) in a sample of blood in order to monitor how well the person's immune system is working.

think we actually believed it would. And certainly Sandy McMillan who was one of the consultants, he kept a very close watch on things. As the cases began to emerge in America, he went across to a conference in New York, I can't remember if it was '82 or '83 but very very early on to discover that yes there were lots of cases of AIDS. There were also guys getting pre-AIDS, for a simple term - they had all kinds of names for things in those days, dwindling syndrome I remember was one of them. They recognised that before you got your pneumocystis carinii pneumonia you tended to be losing weight. You would get skin problems. You would get thrush. And then you'd get the pneumocystis. So there was something winding its way up almost, or its way down, which ever way you looked at it, before you got the serious conditions. And that evolved and probably within the next year or two was called AIDS related complex or ARC. It was also recognised that some guys got generalised lymphadenopathy, so lymph nodes, and of course at this point in the early '80s we don't know what's causing it. People had some fairly exotic thoughts, was it poppers [alkyl nitrites],²⁷ is it just multiple infections, but I think it became fairly clear it was going to be a virus. It hadn't been identified so there wasn't a test. So the only way you could ever diagnose anybody was on the basis of the clinical findings. I think it might have been '83 that we saw our first patient who had AIDS related complex.

3.3 The impact of accurate testing

We can see how the information was filtering through from the United States where there were more diagnosed patients and the clinicians had a little more experience. At this stage, Dr. Scott and his colleague, Dr. McMillan were the clinicians most likely to be seeing people who knew they had been at risk, as they were the clinicians who most regularly saw men who were having sex with men for sexual health checks. There was little knowledge in the wider medical community; that began to change when testing became more available. Dr. Scott describes the moment when it became apparent that HIV in Edinburgh was affecting another group of people and that the scale of the epidemic was serious:

Around the beginning of '85, I was speaking to the virologist and he said 'Do you know I've been testing a few of these drug users who are in Infectious Diseases [the Infectious Diseases in-patient unit within the City Hospital] with Hep B'. There were a lot of guys coming in with Hepatitis, particularly if they'd been in prison. He said 'We've just been doing HIV tests and actually about 40 percent of them are positive'.

²⁷ Amyl nitrate is a drug sold in liquid form and is commonly used by gay men to enhance their sexual experience. For more information: <http://www.talktofrank.com/drug/poppers> Retrieved 9:01:2016

The decision taken by that virologist to look at the stored blood samples was highly significant. It became clear that there was a significant problem amongst injecting drug users in the city. Few of them were regular patients at the sexual health clinic; some of the women who were sex workers would use the clinic from time to time but the majority of the city's drug users were not concerned with their sexual health. If they had a problem related to their drug use, for instance Hepatitis B infection, they were likely to have been referred to the Infectious Diseases service which was based at the City Hospital. That clinic became the main centre for diagnosis, treatment and ongoing support for people whose HIV had been acquired through drug use.

Dr. Mike Jones had returned to Scotland from East Africa and was working in the Infectious Diseases Unit in the early 1980s. He found himself treating injecting drug users within his clinic:

I had been introduced to the problems of intravenous drug use and so that was around Hepatitis B, the septic complications like bacterial endocarditis and so on which I hadn't actually seen. I'd seen Hepatitis B and I'd seen endocarditis many times before, but I hadn't seen it in the context of intravenous drug use (Jones, 2015).

Dr. Jones had become interested in HIV towards the end of his time in East Africa where he had begun to see cases of florid kaposi's sarcoma (KS was a common problem in Tanzania but these were cases unlike the benign form that was usually seen) and pneumocystis carinii pneumonia and he was keen to be involved with a specialist clinic:

I did my first clinic with people who had been diagnosed with HIV infection on November thirteenth 1985. The paper that identified that thirty-five percent of intravenous drug users [were infected] had been published a few months before, and then the funding had come through for setting up a medical service and then Ray [Brett] asked me whether I wanted to start doing the clinic.

Dr. Scott notes that the establishment of a clinic offering HIV care to people who were injecting drug users moved the attention away from sexual health clinics and their cohort of patients and towards the patients who were causing most concern to decision makers within public health:

So the focus then all shifted to infectious diseases. And partly it was concern for an explosive epidemic amongst drug users but also a recognition that there was going to be dissemination to the heterosexual

population. It was going to leave what were quite well recognised risk groups which was gay men and haemophiliacs, and suddenly here's Edinburgh with a third and potentially more explosive problem.

In the days before blood testing was available, the infectious diseases clinicians were less likely than their colleagues in sexual health to have made a diagnosis even amongst those they saw who had been at risk. The early symptoms of HIV related infection such as diarrhoea, sweating, fatigue and lymphadenopathy are all associated with injecting drug use. It would not have been unreasonable to assume that the patient was describing opiate withdrawal (Brettle, 1995:75). The clinicians who were working with injecting drug users did not find themselves making speculative diagnoses in the same way as their colleagues in sexual health. Once testing was available, numerous diagnoses followed. Over 1,000 diagnoses had been made in Lothian by the end of 1989, the majority of those in the city of Edinburgh where there was a known infection rate of 0.3 percent (Brettle, 1995:105).

3.3.1 Testing and Men who have sex with Men

Dr. Dan Clutterbuck came into the field slightly later (1994) than the colleagues quoted above as an active choice:

I started in '94 which was actually the peak year of deaths in HIV in the UK. If I'm honest, one of the major reasons for coming into this was because I was gay and at that time I honestly believed you couldn't be a gay doctor and do something else, which shows how much things have changed. That was only the '90s. I do think the fact that it disproportionately affected gay men, and I never had a particularly strong strain of activism in me, but the fact it affected gay men, and you could actually do something useful (Clutterbuck, 2015).

As a gay man working in sexual health, Dr. Clutterbuck knew first hand how testing, waiting for the results of a test and being given a positive diagnosis might impact on individuals:

Of course it was so massively stigmatised. Without giving too much self disclosure, I can empathise pretty well. But it doesn't necessarily make it harder or more distressing because I think when it's that close to a reality for you, you actually can get your head round it. You empathise to the extent, you're not walking in their shoes and I'm not pretending you are, but you're close enough to it to genuinely be able to see. I've been through mates going through waiting for a test, I've been through partners waiting for a test, and there have been various outcomes. It's

close enough to home that I can think through it as a reality rather than as an abstract thing. I can kind of relate.

Here, we are given a flavour of the anxiety that was associated with taking an HIV test. In the 1990s, results were still not immediate and people found the waiting time extremely difficult. There was nothing to do other than imagine how it would be if the test were positive. Clutterbuck went on to discuss the difference in giving a positive diagnosis today from giving that same diagnosis twenty years ago:

I do think it is [different]. And isn't that, for one thing, it's the crux of why we're seeing so much more I think. Five years ago we were getting ourselves in knots going round saying 'Oh we can't say it's so terrible, but we have to say it's terrible because we still have to stop people getting it'. Well no, people aren't that frightened of it because it ain't that terrible. Collectively I think as a sector we didn't half squirm over that. So although I'm still always ready for people having a very distressed reaction it is less frequent.

This comment is very interesting. There has been discussion in the field in recent years about whether or not it is still appropriate to be alarmist about HIV. On the one hand, there is no cure and it is still a chronic condition. At the same time, treatments are very effective and have few side effects; newly diagnosed people are now told that they will probably die from something unrelated to their HIV. There has been an increase in new infections among men who have sex with men in recent years. It is not entirely clear whether that is due to more testing, as implied by Dr. Clutterbuck, or whether men are taking more risks and there are genuinely more new infections. The latter explanation is often dismissed because we know that people on HIV treatment are not usually infectious. The treatment suppresses the viral load in the bloodstream to such a degree that the HIV virus is rendered ineffective. It is therefore reasonable to assume that there is less active HIV within the community. The people who are likely to be spreading the virus are those who are undiagnosed and/or not on treatment. For this reason, there is an increasing emphasis in the United Kingdom on access to testing in order to ensure that the maximum possible cohort is on treatment and living with suppressed viral load.

Clutterbuck discussed the impact of health education and personal knowledge about the efficacy of HIV treatment on newly diagnosed people:

I think in the past people knew much less about it so they were very distressed when they first heard about it because they still thought it was a death sentence, and that's carried on but to a lesser and lesser extent. Now I think people don't have necessarily this massive initial reaction because most people know that the treatment's effective. A lot of people do, certainly gay men. The prevailing things that I experience when I talk to people who don't know anything about it is they say, 'Is that still a problem?' That's a real strong public perception. So they don't have that initial unfounded reaction of, oh I'm going to die. It's a slower burning reaction. It's adjusting to, actually I've got a chronic disease, this is going to be a pain in the arse, I'm not going to be able to tell anybody, [what about] the effect on my sex life. So they don't tend to have a big reaction initially but I think more often there's more of a delayed reaction. The same as maybe with another chronic disease where it's only a slow realisation not of a false perception of a very real perception of a pretty pain in the back chronic disease.

3.3.1.1 Chemsex - a recent development

Dr. Clutterbuck felt it was important to mention a small sub-population of gay men who are involved in very high risk behaviour. These men engage in what has become known as chemsex. Cambridge Dictionaries on-line has recently added chemsex to its list of slang words and defines it as 'the use of drugs, often illegal ones, to increase pleasure during sex'.²⁸ Practitioners within the field are agreed that the term is generally taken to mean the use of specific drugs - mephedrone, crystal methamphetamine and GHB/GBL (chems) - in order to enhance sexual experience. Most men report initially using chems in the context of sex parties where they are also using 'performance enhancing' drugs such as Viagra. Reports from some of the Waverley Care service users suggest that there are around 100 HIV positive men in Edinburgh who are actively involved in these parties. Parties often last two or three nights and days, during which time men will engage with a number of sexual partners. Mephedrone and crystal meth can both be injected, and, increasingly, that appears to be the favoured method of administration. We also know that personal profiles on dating (hook-up) apps on mobile phones and other devices (which are mainly used to facilitate immediate sexual encounters) include information on whether the person uses chems or not. This information is sometimes coded, but is often quite overt.

²⁸ Retrieved from cambridge.org/dictionary/english/chemsex 9:01:2016

The men who report engaging in chemsex also report riskier sexual practices than those who simply report encounters with other men. The drugs encourage longer sexual sessions which, in turn, leads to a risk of tears and abrasions. Men are less likely to take their HIV medication if they are partying for a weekend and so their viral load may begin to increase making them potentially infectious. The creation of a new cohort of injecting drug users is also a worrying situation. These men do not think of themselves as drug users and are generally reluctant to have contact with mainstream drug services. Their drug use has a different focus from the more traditional opiate users, whose drug use is usually in an attempt to anaesthetise themselves. Chems users are choosing their drugs in order to increase pleasure. They are less likely to know about safer injecting practices or how to manage a new batch of powder which might be of a different strength from a previous batch. There have been a number of reports of complications at injecting sites and some men have caused permanent harm to their veins.

Dr. Clutterbuck looks after men who are regularly putting themselves at risk of infection and sees it this way:

There are definitely a cohort of men and I wouldn't want to overstate it, but there are a cohort of gay men in whom it's either incidental, getting HIV is incidental, or actually there's an attitude of 'might as well get it over with'. Because if they're already on the fringes of a sex party, and it may or may not include a chemsex population and lots of guys who are positive, they're the guys who are having the action. It's that cohort and the HIV is fairly incidental.

Clutterbuck's analysis that there is an ambivalence associated with risk taking is significant. It appears that there is a small cohort of men for whom access to parties and the kind of sex they want is more important than the self care they might otherwise prioritise.

It will be necessary to monitor and analyse the impact of chems on the HIV infection rate over the next few years. Retrospective study will provide important data from which to draw some conclusions about the importance of chems in the transmission of the virus.

This section has shown how the experience of testing for HIV has changed as treatment has become available. It is no longer the case that an HIV diagnosis is one of a life-shortening condition; however, it is still a life-limiting condition.

3.4 The experience of receiving a diagnosis

The formal diagnosis of HIV antibody infection was a memorable event for all of the interviewees who are living with HIV. They were able to describe the episode in precise detail.

Astrid was a teenager when she was diagnosed at an antenatal clinic:

I was seventeen. The first thing he said to me was ‘My dear you have AIDS and your unborn baby will have AIDS and I suggest you terminate this pregnancy’. Live Aid had been on the telly. That came into my head and I thought I’m gonna die, I’m gonna die. And then for whatever reason I remember my next thought was, no I’m not. And I’m not killing my baby (*Astrid*, 2015).

The lasting impact of the way she received her diagnosis can be seen as she describes an experience she had on the thirtieth anniversary of that diagnosis:

I had a flashback, I had a photographic flashback of being told. I can remember where the nurse was standing, I can remember the doctor sitting to my right on the bed with his white coat on and a black beard and his name badge. I remember his name and what he said exactly.

Astrid describes the events of her diagnosis in a way that suggests the words and images have been seared on her mind. This life-changing moment was a marker in the story of her life. The doctor who gave her the diagnosis is someone she has not forgotten. In casual conversation, after the recording had ended, she mused about attempting to make contact with him in order to show him how wrong he had been. Her experience is an example of the lack of knowledge or compassion that were not unusual outwith the specialist HIV clinics that had begun to operate. *Astrid* experienced the doctor as judgemental and patronising. She felt that he had made assumptions about her, based purely on her HIV diagnosis.

Judgemental attitudes were not confined to staff with little contact with patients who had been diagnosed with HIV. Dr. Jones described how some of the

staff in the Infectious Diseases Unit were not comfortable with this group of patients:

I had also seen a variety of staff attitudes within the unit. So there were some people who were really quite antagonistic to people who injected drugs and that was evident. Certainly within the nursing staff some were very pejorative in their kind of attitudes. I think it was a judgement on lifestyle. As the relationship with people who injected drugs grew, those people didn't last long within the unit after that.

These remarks help us to recognise that working with HIV was something that people chose to opt in to (or not) from those early days. We will see later (4.6) that staff within Waverley Care made personal decisions to work with HIV and within that agency as an active preference.

By contrast with *Astrid's* experience, *Sean* had been contacted by the Department of Public Health as part of a contact tracing initiative:

I had become unwell and received a letter from the Public Health Department saying that they had been led to believe that I'd been in contact with someone who had an infectious disease and I was asked to contact my GP who would make the necessary arrangements. And I found out on 8 December 1992 that I was in fact HIV positive (*Sean*, 2015).

Sean, in common with *Astrid*, knows the exact date of his HIV diagnosis. My experience of working with people living with HIV is that this is the majority experience. I know people who deliberately mark that anniversary, especially people who were given a very poor prognosis at the time and have lived many years longer than anticipated. *Sean* also has very clear memories of the events of the day that he was diagnosed. He was seen at the sexual health clinic for blood testing and was asked to return later in the day for his results:

I walked around Edinburgh and one of the significant episodes that occurred was that I walked through Princes Street Gardens as I was walking onto Princes Street and a lady coming towards me ... She suddenly looked at me and said 'Jesus loves you'. I don't know whether I had a hangdog expression and she was trying to cheer me up, I have no idea. But that in particular sticks in my mind. It just seemed so significant. That that should happen that day of all days. I then returned to the clinic and was given the diagnosis. He [the consultant] wasn't happy for me to leave until I had spoken to a counsellor. It was very brief the conversation I had because essentially I wanted to get outside. I smoked at that time and I wanted or needed a cigarette. And then I went across to a public call box near the fire station which is no longer there and I called my parents because my parents knew that I was

unwell. I remember apologising profusely to my mum on the telephone and her only reaction was ‘If I could take it from you I would’.

For *Sean*, the memories are not just of the delivery of his diagnosis but of the immediate impact on his parents. *Sean* had previously told me that he had a clear visual memory of the room that he was in when his diagnosis was given. Like *Astrid*, he has the scene imprinted on his mind. He described the basement room in the clinic, the bars on the windows and peeling paint on the walls.²⁹

Peter’s story is slightly different. He was diagnosed as a result of a non-HIV related medical intervention. He wasn’t told his HIV status verbally, but read it on his medical notes:

My own diagnosis. I’d actually started having involuntary muscle spasms, been to my GP. One day my leg and arm went and I was in the kitchen, so close to knocking the cooker flying. So I was kind of surprised I didn’t get more of a response. I just got a referral to neurology, I didn’t actually get taken in to see what’s going on. So I’d been out on Saturday night, I had a partner at the time, and then Sunday I just collapsed at home. I don’t remember anything but apparently I was taken in to A and E and then I was taken in to intensive care. I was in intensive care for a while and then to a general ward. My diagnosis was a bit strange because I was being sent for an X-Ray, and having worked in the health service I used to look through my notes, and I had the notes in my lap as we went down to X-Ray. So as I was being wheeled down I looked at my notes and on the front page were the letters HIV Positive. As soon as I went back to the ward I said, I know. I could just sense a sense of relief in them because they obviously knew but couldn’t say anything to me (*Peter*, 2015).

By contrast with these service users, Michael delayed testing although he was fairly certain that he had contracted HIV:

My diagnosis came later than my knowledge that I had HIV because it must have been about 1988 or ’89. My partner was diagnosed with KS [kaposi’s sarcoma] so at that point I probably figured out because of my past illnesses.³⁰ I think I’d been on holiday the previous year and had a bit of a what I think was a seroconversion when I was on a Greek island holiday (*Michael*, 2015).

²⁹ Personal journal June 2014

³⁰ KS is Kaposi’s Sarcoma, a form of skin cancer which is an AIDS defining illness.

Seroconversion illness occurs in seventy to ninety percent of people who are infected with HIV. It is the body's response to the onslaught of the virus on the immune system. Symptoms may include flu-like symptoms, rash, nausea and diarrhoea.³¹ The next stage of infection has no external symptoms, the virus is attacking the host immune system but has not yet done enough damage for immunosuppression to be evident. Michael's partner was experiencing symptoms of an AIDS defining illness (kaposi's sarcoma) while Michael was asymptomatic.

Michael's decision to test was purely pragmatic:

I don't think I got tested for maybe another couple of years and I think only because my partner was becoming terminal and we shared a flat and at that point there was no succession rights for same sex couples. I had to apply for a house in my own name so I needed the diagnosis, so I think it was about '90. At that point there was no treatment so I knew my status, I think I knew my status, so what was the point in getting the test. I think it was only because of the housing application that we needed a definite diagnosis.

Michael went on to describe his reaction to the diagnosis:

When I had my diagnosis, and to be honest they weren't very positive in the counselling and testing clinic, they were very negative. In other words, you're going to die, and I'm thinking yes we're all going to die probably but I'm going to do some living at the moment, and I wasn't ready to die yet. I had a lot of stuff to do. But they were preparing me for death and I'm thinking actually I'm preparing for living now. I've got a lot to do, and a lot I want to do and spend good time, quality time with my partner and I didn't feel ill.

Michael describes a reaction that has much in common with *Astrid's* report of her initial reaction. In both cases they heard what the doctors were saying but made a conscious decision that they would not simply sit back and wait for death or a serious infection but that they were going to focus on life and living. Their determination is evident time and again in the telling of their stories.

This section illustrates the impact of giving and receiving an HIV diagnosis and how that has, not surprisingly, been impacted by the advent of effective

³¹ See for example: National AIDS Trust. <http://www.hivaware.org.uk/do-i-have-hiv/signs-and-symptoms?gclid=CO71m5H4nMoCFYMIwwodOAgABw> Retrieved 9:01:2016

treatment. It also notes the change in attitude to HIV, suggesting that it has become a calculated risk for those gay men who are choosing a particular lifestyle. In the next section, we will consider people's descriptions of the impact of a diagnosis as they began to come to terms with their situation.

3.5 Responding to a positive diagnosis

In the last section, we were helped to understand the reality of being diagnosed with HIV in the days before treatment. In this section, we look at the impact of the diagnosis on those individuals and the choices they began, and continue, to make. The people living with HIV who participated in the research each shared something of that part of their story.

Peter found that his life took a very different direction after his HIV diagnosis. He had been working for a Buddhist charity in London and said:

I bumped along as a kind of happy Buddhist until HIV hit and then suddenly saw real realities of suffering and death and pain. My Buddhist beliefs helped because that's the central concepts of Buddhism, but the depth of understanding, I didn't really have enough, that's one of the reasons I left [the Buddhist community in London] (*Peter*, 2015).

3.5.1 The positive influence of spiritual experience

It became clear as my analysis progressed that spirituality was a significant factor for a number of respondents. This section records extracts from the interviews and also includes a relevant case study.

Peter described how he found a school of Buddhism that resonated better for him:

When I was recuperating [from the illness he had when he was diagnosed] I went to Samye Ling.³² I happened to pick up the Tibetan Book of Living and Dying, just saw it in the bookshop and bought it for something to read.³³ So I was in Samye Ling and I was reading it and it was a real revelation because there was all this strand of Buddhism and it dealt a lot with pain and suffering and death and dying and one of the things I found difficult to cope with was this huge amount of pain and what do you do with it. Not physical pain so much but pain of losing people and seeing people in pain.

³² Kagyu Samye Ling Monastery is a Tibetan Buddhist Centre at Eskdalemuir in Dumfriesshire.

³³ Sogyal Rinpoche. 1992 *The Tibetan Book of Living and Dying*. Harper Collins

In this section, *Peter* begins to reflect on the impact of his diagnosis and, in particular, to acknowledge the depth of emotional and spiritual pain which he and his friends were facing. His experience at the Samye Ling centre was pivotal in changing the focus and direction of his life.

Peter had observed a range of responses amongst his community in London. He offered some analysis of what had been happening:

And one thing else I noticed in London when people were dying they were acting in one of three ways. A lot of people went into total denial and got heavily involved in drugs and alcohol. I saw so many people do that. A few people committed suicide because they just couldn't cope with it - there wasn't much you could do at the time for HIV. Other people, perhaps this isn't the right word but it's really acceptance. 'That's great, there's nothing I can do about it'. And in very few people it actually transformed their life in a positive way. Not, yeah, this is fun, but I heard some people saying HIV diagnosis was the best thing that had ever happened to them, which seems a bit kind of perverse. They said it's because it really made them re-evaluate their life and I can understand that from my own diagnosis. A few people did become more compassionate. You know London's very hedonistic but some people did turn more to helping each other and trying to be more understanding and to get the bigger picture.

Peter is describing something here which I have heard from many service users. In particular, amongst the cohort of people in Edinburgh who were infected through injecting drug use, a change of lifestyle and the improvement in health, mental, physical and spiritual that goes along with that has been a defining feature for many people. One woman, whom I will call *Julie* shared the following story.

Julie was in hospital. She had pneumocystis carinii pneumonia and was close to death. She was in isolation in the City Hospital. She had what she described to me as a vision. She had an encounter with Jesus, an encounter that, for her, was as real as the encounters she was having with medical and nursing staff on the unit. As a result, she found herself able to believe that she would live rather than die. The story she told has resonance with stories of the Saints of Christian history. For instance, St Ignatius was very ill when he had his conversion experience; descriptions of visions are normal in commentaries on the lives of the Saints. *Julie* decided that if this experience was real and she was going to live she owed it to Jesus to choose a different kind of life.

Up to that point, she had been heavily involved with drugs and was finding it difficult to care for her children. The drugs were her crutch both before and after her diagnosis and she was unable to see any reason to stop using them. She believed that her children would be better off without her as her prognosis was poor and they would eventually be taken into care. As a result of the decision she made after her spiritual experience, she left the ward drug-free and never injected again. She then began to explore the options for accessing support and engaged with a parenting agency which had a significant influence on her approach to life and to her children. She moved to a different area of the city and gave herself permission to have a fresh start. When I first met her, she was one of the more stable service users I knew. She was able to offer support to others and to share something of her own story. She was chosen as a representative of HIV service users to travel to international conferences, representing her peers on two separate occasions.

Julie's story is a good example of the way that an HIV diagnosis, and in her case a near death experience, had a positive impact. She is clear that she would have been dead a long time ago if she had not stopped using drugs, and equally clear that she would not have stopped without the diagnosis. The intense spiritual experience she had was life-changing, but only one part of her story. The other part was her HIV diagnosis and her belief that she had no future. Her descent into chaotic drug use had accelerated with her diagnosis and she had lost hope. The affirmation she received from peers and professionals when she stopped using drugs and turned her life around was enough to convince her that she had made the right decision. The new experiences she had were more than enough to compensate for the gap left in her life when she became drug free. HIV enabled *Julie* to live in a way that she had never imagined would be possible for her.

Peter was also influenced by his spiritual life and he elaborated on what made the difference for him:

I'd say it's my Buddhist beliefs and Buddhist practices that have got me through. It's not just getting through but it's also trying to find something positive out of it.

Astrid found that a connection with her faith community helped her to cope:

I did a lot of self talk and then I re-embraced the faith I'd had as a child. I had a really strong faith as a child. I don't know why I did. I remember being seven, eight, nine and I would just speak to God and it was real for me. So I started to rediscover that. I thought I've got back-up here.

She began to go to church and found a place of support and hope within that community. However, her contact with that particular church was not entirely positive. She had been made a Eucharistic Minister and was actively involved in the congregation in a number of ways. She decided to disclose her HIV status to the priest, whom she considered to be a friend, and was met with an unexpected response:

I wasn't allowed to administer the chalice in case I passed on my disease. And that just stopped me in my tracks. Instantly I felt that I was head down, unworthy, worthless, and being judged again. He said if people ever found out then he would get into trouble, and I thought, OK so it's a big bad thing again and everybody out there thinks I'm scum and you're just underlining the fact that that's what people think. It made me feel really bad again so I stopped going to church.

Sadly, this is not an unusual story. Clergy are often ignorant of the facts and fearful of how members of their congregation might react if they discovered that someone who was living with HIV was active in the life of the church. I have had a number of conversations with clergy who have discovered that there is someone living with HIV in their congregation and wondering who needed to know. The answer, in all situations, was no-one.

Despite her negative and damaging experience, *Astrid* continued to gain strength from her faith. She was encouraged when she had an experience of opening her Bible and alighting upon a verse that was particularly enlightening for her in that moment:

And my faith has certainly strengthened me because all through that, from that moment when I got that Scripture to read, and I thought you [God] know what I'm meant to be doing. You have plans for me. And I'm just gonna go with it. And I'm gonna trust you and I'm gonna have confidence that whatever happens you're going to be there.

3.5.2 HIV as an agent for positive change

I have met many people who tell me that HIV has changed their lives for the better. People have made health related decisions, have changed their attitudes, have faced their own mortality and as a result see themselves as very

different people. *Astrid* describes her own feelings about the way she has changed:

I don't think I would have been as understanding or as thoughtful a person as I am now. I'm not always like that, but my default setting is to be thoughtful and kind. And to give someone time. Whereas I might have been a really selfish horrible person if I hadn't had this diagnosis and I might have just been, you know, completely materialistic and all these things but it's definitely, it's made me who I am. Because I was a child and I wasn't just seventeen, I was a very, very young seventeen. I wasn't streetwise at all in any way. I didn't know much about much. I was still embarrassed about getting my periods. That's how immature I was. It has, it's as if it's just picked me up and just moulded me and put me back down over thirty years. And it's a funny thing to say but in a way I'm glad. I'm glad because I don't feel anybody's any better than me and I don't feel anybody's any worse than me because I think, 'There but... [for the grace of God go I]'

So it has made me really aware that I just take people where they are and I would love to see the person I would have been actually if I hadn't, if this hadn't shaped me, because there's absolutely no question that it's shaped me.

Astrid is a good example of someone who has sufficient self-awareness to recognise the impact of the HIV virus on her life and the possible alternative scenarios which could have evolved for her. In particular, I note the impact on her confidence and dignity, her ability to see herself as equal to anyone she encounters. HIV was the catalyst for change in her life.

3.5.3 Alcohol and sex as coping strategies

In contrast, Michael described his initial response which was much nearer to the attempts at denial that *Peter* talked about when he described some of the unhealthy responses he had witnessed:

Alcohol worked for me. After my partner died alcohol makes you forget but there again you end up being more depressed and there were probably periods of self harm - I wasn't working then (Michael, 2015).

Michael is very honest about the way he tried to escape from his own reality. He used alcohol, he sought solace in sexual encounters and he tried to convince himself that those strategies were helping him to cope. In fact, they were having a negative impact as we can see in the next quote from his interview, where he also describes how he began to turn things around:

Doing a little bit more made me think I don't want to be comatose the next day, I want to do something and get out, whereas previously I was probably just going out to the bars etc. and just getting rat-arsed and staggering home, or getting a taxi home if I could afford it, or going home with some stranger. [Laughs] Going home with some strange man and hopefully not getting into too much danger. There were a couple of times during that period when I took somebody home who beat me up and stole money and stole watches and things like that. I think there was one just after my partner's death. I think he'd bought me a watch and I can't remember if it had been that Christmas before he died, and the guy who I went home with stole the watch and I think that was the kickstart of thinking you can't do this all the time; you're vulnerable.

Although religion wasn't at the heart of his recovery, a focus on life and positivity began to make a difference. These principles are at the heart of much religious practice. For instance, practitioners of Ignatian Spiritual Direction are trained to listen for that which is 'life giving' in their work of accompaniment. Michael was able to recognise his own vulnerability and to make a conscious decision to take better care of himself. He was effectively choosing life. HIV was the catalyst for positive change in his life.

3.5.4 Making lifestyle changes

Michael described the way that active change came into his life:

I think the game changer was meeting up with my friend *Robin*. He'd just been really recently diagnosed and came up to Edinburgh to stay with his sister and we just gelled right from the start when we met at the mens' group, and he was the main driver for me.³⁴ He was the one who would come round and say we're going out, I've got the car we're going a drive, we're doing this. And he was the one who took me away from that brink. He's the person who probably took me away from that path. He was a bit of a nag and to be honest if it hadn't been for him I think I'd have come around but it would have taken a lot longer but he was the mainstay in my life.

Annie, who was the earliest diagnosed of the people I interviewed, was told to make immediate changes to her lifestyle when she was discharged from the hospital after her diagnosis:

When I left I got a bit of paper. There was no support services. There was nobody you could phone up and talk to. Because there wasn't a very many people diagnosed then and I got sent home and told to be a good girl. I wasn't to have unprotected sex, I wasn't to use people's

³⁴ Waverley Care hosted a gay men's group, Juice at Solas, its community base, from 1992-2007

toothbrushes, I wasn't to have anal sex, I wasn't to get my ears pierced or tattoos. I was to be safe. To use condoms. Not to use any more drugs. That's what I got told when I left the hospital.

I stopped using. Fortunately, all the drug users were in the jail and there wasn't any heroin on the streets of Edinburgh. That's how I got the abscess. There wasn't any heroin and I used tablets and my veins were all thrombosed so I injected this stuff into my arm and that's how I got the abscess. What heroin there was was hardly worth using. So I stopped using drugs. I was also a prostitute. I stopped because I didn't need money for drugs, I didn't need to sell my body for money to get drugs (Annie, 2016).

Annie's story shows how closely drug use and street prostitution were linked for her. She worked on the streets as a means to an end. She has told me that she was not very good at shop-lifting and so she felt that she had no other choice but to work as a prostitute as that was a guaranteed way to earn enough money to keep her in heroin. There were, of course, risks associated with that decision. It was not uncommon for women to be victims of physical and/or sexual attack, either from customers or from other women. There was one woman I remember who carried a knife and regularly forced other women to hand over their money to her. There were also men, often drug dealers, who terrorised the women and abused them in a number of ways.

Annie's story also shows how little was known of HIV and how the medical profession was desperately seeking something to say to people who were testing positive. I am struck by the fact that the detail of what was said thirty years ago is still clear to her, showing that she absorbed the information she was given, perhaps through a combination of fear and uncertainty.

3.5.5 Impact on sexual relationships

In contrast to the stories above, *Sean* responded to his diagnosis by deciding to put limits on the relationship with his partner. He describes the period of time after his health began to recover as a time of rebuilding:

It was a difficult rebuilding because unfortunately my partner was an alcoholic, but we had enough in our lives that it made a relationship worthwhile. We moved to the countryside, it was quite idyllic. From having taken away the possibility of my being able to build anything worthwhile in my life to finding that this relationship was worthwhile and things could be built from that, helped a great deal. But then our relationship ran into problems, not because of his alcoholism, but because of my feelings towards him growing and deepening and I just couldn't

assume the responsibility of ever giving him HIV. We always practiced safe sex but at the same time I just, he meant so much to me, I thought I could never, the guilt I would feel if ever I transmitted that. And our relationship floundered then. It was just, I couldn't get my head round it. It was omnipresent. We were still tactile but full sexual relations were out (*Sean*, 2015).

The Scottish Government funded a project in 2011 which aimed to use the lived experience of people living with HIV in Scotland to inform and educate. The task was to interview a number of people and to use the transcribed texts as source material for educational material which has been produced for schools, churches and medical settings. The work was contracted to Waverley Care and became the HIV Always Hear campaign.³⁵ The HIV Testimonials document includes verbatim case studies. My research develops some of the themes captured there and gives a more extensive understanding of the impact of HIV on the lives of individuals.

One of the subjects who participated in the HIV testimonials interviews was a young man who was born with HIV. He discussed the impact of living with the virus on his sexual relationships:

I've not been in a serious long term relationship yet. I want to be a wee bit older so I can have a deeper bond. That takes a long time; it needs to be a slow process so I can build up trust with the person because I would want to tell them. If you told a sixteen or seventeen-year old you had HIV they would probably run a mile. So I think I want to wait and meet someone more educated, someone older who would deal with it better. I live with HIV so I am very aware of what could happen, and I would never put anyone else at risk. There is no excuse for unprotected sex, condoms aren't hard to get. At my college you can pick up as many as you like for free. So why wouldn't you? (HIV testimonials, 2011:4).

Another person whose story forms part of the HIV testimonials is a gay man in his early sixties. He talks about the impact on his intimate relationships:

I was rejected by my family, my lover, my church, I can't take any more rejection. So I've made the decision to stay celibate. I have chosen isolation over the risk of losing someone precious when I tell them I'm HIV positive. I suppose the difficult times come when you wake up every Sunday morning and you have breakfast on your own. The older I get, the more and more frightened and lonely I become. I suppose if I met another gay man who was HIV positive, I would consider a relationship but the

³⁵ www.HIVAlwayshear.org

chances of that happening are very, very minimal. I've convinced myself that I'm going to fly solo for the rest of my life (HIV testimonials, 2011:20).

These three vignettes show us how seriously people take their diagnosis and how they begin to take responsibility not just for themselves but for any sexual partner they have or might have. These men all made decisions to avoid sexual relationships as a direct response to their own moral compass.

The responses to diagnosis begin to hint at the issues associated with HIV stigma. We will now consider the impact of stigma on the lives and lifestyles of the interviewees.

3.6 Stigma

Stigma is a theme that occurs and recurs in discussion of HIV. To offer a definition, I follow UNAIDS which describes HIV-related stigma and discrimination as:

a process of 'devaluation' of people either living with or associated with HIV and AIDS...Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status (UNAIDS,2007:9).

Gillian Paterson, in her thesis on stigma, also follows the UNAIDS definition and enhances it by suggesting that stigma is 'a dynamic process of devaluation that "significantly discredits" an individual in the eyes of others' (Paterson, 2007:12). This definition is helpful and comprehensive. HIV-related stigma has left some of the individuals I have worked with feeling diminished and de-humanised. People describe themselves as becoming invisible, of finding that they no longer have any status within their communities, or that they have become defined by their HIV.

Astrid's experience was one of deep despair and imagining there was no hope in her future:

All through that time [the late 1980s] the difficult part was I knew what was going on for me and the stigma in society was huge. So I had to keep it all to myself. And because I'd split from [my son's] dad, I thought well nobody's going to want me. Which was backed up by my dad when I told him, he was like, well that's you now eh. Nobody's going to want you now. So I believed it, you know nobody's going to want me and I'm not gonna tell anyone and I'm not going to make any close friends. So I went

through my twenties not making any friends, being very insular and very guarded. People must have thought, she's a bit strange. I just didn't want people to get to know me and ask questions, so I kept myself very isolated, which actually to this day has some impact on me, because people have got friends from college and from their twenties and I don't have that.

Recent conversations with a group of people who are living with HIV suggest that *Astrid's* experience is not unusual.³⁶ They all discussed how they had no contact with friends from before their diagnosis and that their circle of friends had all been gained post- HIV and was mostly comprised of people who are also living with HIV. One service user told a story of a woman whom she had known for more than thirty years. When she disclosed her HIV status, the 'friend' put the phone down on her and now crosses the road if she sees her in the street. HIV related stigma can be linked with the isolation which is experienced by many people.

Liz Marr gave an example of the impact of HIV-related fear and stigma. Her extended family had been directly affected and she told me how her cousin and her aunt created a veil of secrecy:

My cousin had HIV and we didn't know what was wrong with him until he was fairly advanced and fairly unwell. He already had AIDS-defining illnesses at that point. I think his brain had been affected, although we were not allowed contact with him. He didn't want to see anybody (Marr, 2016).

3.6.1 Parallels with leprosy

Stigma has also had an impact on those who care for people who are infected with the HIV virus. Dr. Mike Jones was aware of the fear associated with HIV:

The first thing was in terms of its impact on me, this was something that I kept very quiet about. I didn't tell, well obviously my wife knew, but I didn't talk about it with other people. That wasn't because I was ashamed of it but because there were a lot of stigma issues surrounding HIV, and therefore to talk about the fact that I was working with HIV positive patients, I didn't talk about this with my father and step-mother for instance. I just said that I was doing work. That was not because I was ashamed to be involved. I think actually I felt that it was a kind of personal privilege in a way to actually be involved in caring for people who had a stigmatising disease. The biblical parallel obviously is with leprosy. And Jesus reached out to lepers, touched

³⁶ Personal journal May 2016

lepers, did the things which other people didn't want to do with what was considered to be a transmissible disease.

In her interview, Annie mentioned feeling like a leper:

You do feel a bit like a leper. You were feared to go to people's houses because you didn't know how they were going to react once they knew your status. You were scared to tell people because of their reaction. Because they were frightened. If you went to somebody's house and they gave you a cup of tea, they'd throw the cup in the bucket. You were feared to use people's toilets because they were feared if you used their toilet they might catch something off the toilet seat. And even giving you a kiss. People who would normally greet you with a kiss and a cuddle they were feared to touch you. Like you were really infectious. It was quite frightening.

These two extracts give a clear sense of the anxiety that people felt, the assumptions they lived with and the secrecy that became a part of people's lives. It is interesting to note that the stigma was experienced by people working in the field as well as by those people who had been diagnosed as positive.

3.6.2 Stigma in medical settings

Dr. Gordon Scott mentioned the impact of stigma within the hospital environment:

The stigma is not as bad as it was but it's not gone by any stretch of the imagination. And there were some horror stories from the early days of people being treated very badly. Very insensitively sometimes, but also more or less kind of mark of Cain on the door.³⁷ And very visibly treated differently in a way that would clearly compromise confidentiality. A lot of basic medical principles flew out the window (Scott, 2016).

Annie, who was diagnosed in 1985, has clear memories of the stigma she encountered in a medical setting. She was initially in the Royal Infirmary and was moved immediately to the Infectious Diseases Unit when her HIV was diagnosed:

[The stigma] was terrible, I was in the Royal Infirmary and the doctor told me the test had come back positive and I was in a room with three older women. They practically threw me out because they wanted to fumigate the room, and they were all going about with big suits on and gloves and masks. Then getting taken up to the City Hospital there were two

³⁷ Genesis 4.

ambulance men. Usually one sits beside you and one drives the ambulance. But they were all suited up too. And all it was, I had an abscess on my arm, I wasn't pouring blood anywhere.

Her experience of dental care was no better:

It was the same when you went to the dentist. You could never get an early appointment because they wanted to fumigate the room after you'd been. So you always got an appointment late, the last appointment of the day. And they were like big robots. You couldn't see the dentist 'cos he had the hat on and like a big boiler suit and the gloves. You'd get seen to and then you knew as soon as you left they were going to fumigate the room.

Sean also had a bad experience with a dentist:

I was in the dental hospital when I had to go in for emergency dental treatment, and the dentist read my notes and she turned on her heel and went marching in to the senior dentist. And I knew exactly what was being said. And she just walked out and glared at me and the guy had to see to me himself. When I mentioned it to the regular oral surgeon he was profusely apologetic.

Liz Marr described an example from her professional experience. This was the story of a woman I knew well who died of bladder cancer. She was an older (mid sixties) woman whose cancer was diagnosed and treated very late. Marr remembers:

She went for one particularly difficult appointment and it was a guy who had said we can't possibly operate because of your HIV status. She had quite a few appointments where she had to keep getting her [HIV] consultant to say 'this is ludicrous, she's on anti -[retro]virals, she's undetectable, there is no reason why you would not be operating on this woman'. Eventually she did get it but she never really recovered. She had been losing weight at a rate of knots for about a year before she got that diagnosis. That's quite an extreme experience (Marr, 2016).

The next example is of a very recent event that I witnessed. In January 2016, *Alex* was on a respiratory ward with end stage lung disease. The staff were not managing his pain well and he was regularly asking for more medication. He was also waiting for an assessment by the palliative care team; there was no question about the fact that *Alex* was nearing the end of his life. *Alex* had a history of injecting drug use and was on an opiate-substitute maintenance prescription. While I was visiting, *Alex* began to look very uncomfortable and he told me that the pain was really bad. Observing him, that seemed to be the

case. He ‘buzzed’ for a nurse who arrived and told him that he couldn’t possibly be experiencing pain on the amount of medication he had been given. She told him that there was no possibility of him having more at the moment. My reflection in my journal was this:

I feel very sad to have been in a position where I observed this interaction and felt unable to intervene and make a difference. It seemed like a very judgemental and cruel response to a man who was in pain and nearing the end of his life.³⁸ I can only assume that the nurse was labelling *Alex* as a ‘junkie’ who was living with HIV and therefore simply looking for drugs in order to feel stoned.³⁹

Three days later, *Alex* was moved to a hospice where he was treated with dignity and respect. He was given an adequate amount of medication and died comfortably and peacefully.

These examples, in clinical settings, show the extent of ignorance and preconceptions that abound and continue to interfere with good clinical intervention. The compassion and care that might be expected within medical settings were not routinely in evidence. Occasionally, people would tell a story of a nurse or care assistant who was kind to them, but those stories were unusual, and the individuals have been remembered because their responses were different from the norm. These attitudes exacerbate the feeling many people have that the diagnosis has de-humanised them, that they have become simply a carrier of a virus rather than a complex human being.

3.6.3 Stigma based on pre-conceived assumptions

Assumptions are often made that people who are living with HIV in Edinburgh are injecting drug users because there has been extensive press coverage of the epidemic amongst drug users in the city. People report being shouted at in the street, called ‘junkies’, even those who have rarely or never used non-prescription medication. Liz Marr gave an example of the impact of assumptions within a medical setting:

³⁸ Alex died 5 days after this event.

³⁹ Personal journal January 2016

One guy had gone for X-Ray and he was to have dye injected, and they made a comment about his veins because [they assumed] he'd been a drug user. He was treated badly and treated differently because of his perceived behaviours. In the end they wouldn't take the bloods because the guy said he couldn't take it because he was a drug user and his veins were all shot, so he didn't want to try. Now, knowing that person, [I know that] his veins stuck out like tubules all over his arms and he'd never had problems giving blood.

Marr discussed an example of the challenges that faced staff who were working at Milestone and found themselves dealing with the assumptions and prejudice about the unit:

The biggest difficulty I had about saying to people where I worked was with taxi drivers. They would pick you up from here [Milestone] and were taking me to a meeting or whatever, they would all say, 'What is it they do in there?' You'd get into an ignorant conversation about, 'Well people brought it on themselves', and 'I've never put myself in that position. If they're a junkie they've got to expect to get things like that'. The amount of taxi journeys that I've had where I've said, 'Well, how many times have you had sex without a condom on, have you ever put yourself in that position? Because what you're describing is not the complete picture'. A lot of people would say, 'That's right, you don't really think about that', but there's equally people who would go, 'Aye right whatever'. In those early days there was still that belief that people brought it on themselves, they got their just deserts really for choosing that kind of lifestyle and choosing that way of behaving. And 'I would never put myself in that position and it would never happen to me'. It has shifted and people do realise it doesn't affect people in that way and actually it is harder to catch. But there's still that little cohort of people that believe that it's about junkies and gay men and that's it. It's really frustrating to be honest.

3.6.4 Stigma within the community

Sean began to realise that people within his parents' community were treating him differently:

My father's best friend had died and I took him to the funeral. My father was a pallbearer. So I was going to be sitting on my own. All of the people were friends of my parents. I can remember standing outside waiting on the coffin to arrive and they were in different groups, and I went up to speak to the first group and they just cut me dead. And similarly to another group of people. It was so obvious, they more or less turned their backs on me. Some of these people were neighbours of my parents when I was growing up. It re-emphasised some of the experiences I'd had with ex school friends who had quite literally walked past me in the street. When it began I questioned whether it was because I was gay or it was because then it was fairly obvious that something was wrong and

they could draw their deductions. I was fairly skeletal and emaciated facially. I think these people put two and two together, had surmised what was wrong with me, and they literally would walk past and cut me dead.

Annie was able to recognise the hidden nature of the disease:

In the beginning you'd maybe see somebody at the hospital and you'd see them in your community, and they would deny they had it. They wouldn't be open. 'I've not got that disease', but you knew they did have.

These remarks show how, even within the most affected communities, the fear of rejection resulted in people attempting to hide their HIV status. Waverley Care was chosen as a name for the Scottish HIV charity because it was anonymous and disclosed nothing about the client group. There were strict guidelines on confidentiality within all of the voluntary sector HIV agencies. For instance, staff would never acknowledge a service user in a public setting unless the person approached them first.

Sean gave a powerful description of an experience he had in his home town:

I'd been staying with dad. Dad was out that particular night and I'd run out of cigarettes and I thought will I go to the late night shop or will I leave it. And I decided to go to the late night shop and there were a group of kids, teenagers coming towards me, and one of them was larking about essentially with his back towards me. And I was trying to negotiate the way so that he wasn't going to come into contact with me. And when he saw me - at that point I was particularly skeletal - and my cheeks were far more drawn in than they are now and he just suddenly looked at me and said 'diseased or what'. I just, I don't know how I got back to the house. I was so upset at that. It was somebody who knew nothing about me. They didn't know me. It was just hurtful.

This example shows how the HIV related stigma can become internalised. We have no idea whether the young person concerned was referring to HIV or to some other condition that he imagined *Sean* might have. However, the immediate assumption on the part of the person living with HIV is that their condition is apparent and that they are being vilified for that reason.

3.6.5 Stigma and families

Nichola Frith is the Children and Families Manager with Waverley Care. She has been in that role for twenty-five years. In her work, the impact of stigma is experienced most clearly by children who find themselves living with secrets or half-truths, usually told by their parents in order to protect the family from HIV related discrimination. Many of Frith's clients were the same people whom Annie encountered in her community, and who felt they had to be secretive about their situation:

I think because of all the stigma that's surrounding HIV and the way the families have to cope with that stigma, most of the time people can't be open about their HIV status. And I think it's true even in this day, but I think it was worse, a bit more challenging in the past. I think for parents the mix of HIV and sometimes chaotic lifestyles and then within that trying to bring up children, it's not a good mix. And then of course parents dying and children having to deal with that as well. They're dealing first of all with stigma and HIV and then they're dealing with probably the biggest bereavements you can deal with in your life. Losing your parents (Frith, 2015).

Frith talked about the impact on children of living with such an enormous secret within the family:

Children feel things. So they'll be living in a family and the parents might not be telling the children that they themselves are HIV positive, or actually the child may be positive and they're not telling the child. But I think the children can feel that and they can also hear things. They also tune into their parents talking about their illness to other people. And quite often I've had children who will have overheard their parent maybe talking about the medication, maybe mentioning the words HIV. Children will maybe come into the centre. They'll see leaflets, they'll maybe even read the leaflets. And I've had a few children who've actually challenged their parents eventually. Do you have HIV? What is HIV? Have I got HIV? Children know. I know from my own son, you wouldn't hide anything from him. He's very open and he'd always ask questions about it. But I think a lot of the children I work with don't ask questions because they don't want to upset their parents. I think just living with that burden is really difficult and it can have a huge impact on your emotional wellbeing. I think a lot of children have difficulties at school because of that. They might be going into the class and trying to concentrate on the work in the class but they're quite emotionally distressed and so they fall behind. I think to be honest with children about your status is a much better way to be. I can see why parents want to protect their children in every way and I've always said to parents you have to do it in your own time. You have to disclose to your child in your own time, because you have to be there to support your child. Quite often parents maybe never ever get to that point. I think the children when they do eventually find out, and often maybe not from their parents, can feel betrayed.

Frith is describing here how the impact of living with stigma leads to a fear of disclosure and an environment where people are living with part-truths and questions that cannot be asked. Parents, in an attempt to protect their children, can create an atmosphere of distrust and may even damage the relationships with their children.

A young person who was interviewed as a participant in the HIV Testimonials Project was born with HIV and describes his experience of being a young child and not knowing about his medical condition:

I didn't find out until I was eleven. At primary school I remember going for check-ups every few months. One time, when I was about four or five, I came in late to school. All my classmates asked where I'd been, and I told them I was at the hospital for a check-up. They wanted to know what for. Their questions confused me because until then I just thought it was normal for everybody to go for check-ups. That's when I started to wonder why it was different for me. Mum waited until she felt I was old enough to understand a bit more before telling me. But at eleven, I still didn't really know much about HIV. Even the doctors and nurses at the hospital didn't explain it fully to me. They were very kind, but I never really understood what they were talking about, I only remember being told by them that I had to take my medication. It wasn't real to me until I reached the age of about fourteen or fifteen when we started talking about it in school. I'd always known something was wrong, but the seriousness of it didn't hit home until then. I shut myself away for a couple of months, and then after that I just thought, 'Well, I might as well get on with the medication and become a normal person' (HIV testimonials, 2011:5).

3.6.6 Stigma in the public arena

Karen Docwra is the fundraising manager with Waverley Care. She gave me a recent example of the impact of stigma on her work:

I think it's tragic that we're still after all these years not really a whole lot further forward with stigma. From a fundraising point of view that is still an issue. We had one person who contacted us who was either the brother or sister of someone who uses our services and is HIV positive and said I want to run the Edinburgh marathon for you. Is there any way I can run the Edinburgh marathon and have a Virgin money giving page without people knowing it's coming to you? And we had to turn round and say well no, there's not. So we encouraged them to support BBC Children in Need (who fund one of our services) or to choose a mental health charity because so many of our service users have mental health issues. It's just awful and it's challenging (Docwra, 2015).

Liz Marr shared another recent example of the impact of stigma:

One of the hardest things for me was when a relative's hands were chosen for the Nelson Mandela memorial [an HIV memorial at the Edinburgh City Chambers which features hand prints and was opened by the singer, Annie Lennox] and we went for the opening of that. He at the time was fifteen or so and had to watch it from a window above the square in the City Chambers because of the perceived stigma that he would have got from school friends and from wider networks like family networks and things. Because he and his mum have kept that diagnosis secret. I think that says a lot about stigma in itself in that they don't feel comfortable enough to actually say to family members that this is the situation. And I found out by accident because of where I work and because of the services that she was accessing.

3.6.7 Summarising

Stigma is, undoubtedly, one of the most significant factors in day-to-day living for people who are HIV positive. They can never be sure how a disclosure of their HIV status will be received or who it is safe to tell. Gillian Paterson, in her PhD thesis, suggests that:

In trying to understand AIDS related stigma, the connection between HIV transmission, sex, sexual orientation and sin has been exacerbated by the historical connection between sex, disease and sin. [...] In addition to syphilis and AIDS, where the mode of transmission is primarily sexual, historical and contemporary studies of cholera, leprosy, plague, tuberculosis and other fatal or life-changing diseases have shown that this association is made even in cases where sexual contact is not the mode of transmission. In all these the 'meaning' of the disease, together with the religious and cultural baggage it carries, has been inextricably linked with the idea of disease as a punishment for sexual sin (Paterson, 2007: 177).

In the Edinburgh situation, there is an additional overlay which is the use of injectable drugs, perceived generally as a dirty and dysfunctional practice. This means that those who were infected either through sexual activity or through injecting drug use were assumed to have engaged in immoral activity and therefore perhaps deserved their diagnosis as a punishment for their behaviour. Inevitably, this then creates a class of 'innocents' who are not seen to be responsible for their own HIV status, that is children and people who were infected through blood products or transfusion. This theory is supported by the experience of the Waverley Care fundraising team who have found on numerous occasions that fundraising for children affected by HIV is far more successful than fundraising for adults who are living with the virus.

The impact of stigma is undoubtedly a significant determinant on the mental health of people who are living with HIV. The pressure of living with fear, of keeping secrets and making up stories has a negative impact. Gradually, people are beginning to challenge that way of responding. Some of the participants in this research have chosen to use their own names. Some of the Waverley Care service users and others in the UK have chosen to speak out and to be identified as people living with HIV. As more people take that step, we must hope that they will have an impact on the experience for the wider community of people.

3.7 Mortality

I will now discuss the impact of an HIV diagnosis on people's sense of their own mortality and I will consider the impact of bereavement on this cohort of people. The subjects of my research were all under thirty when they were diagnosed and have all been bereaved on numerous occasions as a result of HIV related illness. They were young people who might have imagined that they were just beginning their adult lives, only to be told that they had a very short future ahead of them.

Sean has a very stark description of how that felt:

Having taken onboard that you had HIV, I then naturally formed questions in my head, the principal one being, how long do I have, because at that time it was more or less a death sentence dependent on how far down the road you had gone. And I contracted PCP (pneumocystic carinii pneumonia) very shortly, within six months to a year of the initial diagnosis, so I became full blown fairly soon after finding out that I'd been positive.⁴⁰ That changed me. For some time, I felt quite fatalistic. I saw no point to many things. And many things that I had been interested in before, things that I enjoyed before, I just couldn't see that these things were any more going to be part of my life. Being full blown with AIDS was going to be the be all and end all. It was all consuming. It never left my mind from one day to the next. It was essentially the first thought in the morning as I woke up and the last thing as I went to bed at night. You heard different stories of other [AIDS] defining illnesses and illnesses that other sufferers contracted and your natural worry was that you would head down the same road.

Sean's account gives us an insight into the burden that was experienced by people who had received this diagnosis. There was no active treatment

⁴⁰ Full blown is a colloquial term used to describe the diagnosis of AIDS.

available and he was not really offered any kind of hope. Rather, he was classified as having ‘progressed’ to AIDS, which was a World Health Organisation classification based on the individual having a low CD4 count and presenting with certain opportunistic infections which were described as AIDS defining conditions. The lack of hope is a recurring theme.

Dr. Gordon Scott described what he observed in the earliest days:

The first World AIDS conference was held in Atlanta in April 1985 and Sandy [McMillan, the consultant physician at Genito Urinary Medicine] and I managed to cobble together enough money to go to that. My abiding memory of that conference is the number of patients that were there. They were there desperately looking for effective treatment, a cure you know. I had never seen kaposi’s sarcoma before then and there were guys wandering around this conference covered in kaposi’s sarcoma. And the desperation, honestly it was palpable. Have you ever seen *Dallas Buyers Club*?⁴¹ They didn’t get that right. They did not get the desperation. These guys were desperate. They were gonna die. There’s one scene in that film where there’s a big long queue of guys waiting for, I can’t remember what they were waiting for. They didn’t get the desperation that that queue would have had. They also didn’t get the fact that half the folk would have been in wheelchairs or lying flat out on the ground because they would be too ill to stand in a queue. So the standing queue was wrong. The despair, the need, they didn’t get that. And to see these poor guys going from room to room hoping that someone’s gonna say ‘We’ve found this drug, we think it’s gonna be beneficial’.

This extract gives a real flavour of the impact on Dr. Scott as a clinician with little information and nothing tangible to offer to his patients. *Sean* described how bleak the experience was for him and we see how it was equally bleak for the professionals who were attempting to offer clinical care.

Nigel Cook described how he witnessed the depth of people’s desperation in the UK:

I remember once I was down at a meeting in London and they had an outdoor rally in Covent Garden, this must have been mid to late ‘80s. I remember people being very hysterical and what was being expressed at the time was a desire that somebody would do something about this. Because it was the 1980s, Thatcher, and nothing was coming from Government, so there was a desire that somebody wake up to this and be compassionate and try and find some cure, try and find something (Cook, 2016).

⁴¹ Craig Borten and Melisa Wallack *Dallas Buyers Club* IMDb. Directed by Jean-Marc Vallee. 2013 USA. 2014 UK.

Desperation is the common theme throughout these memories. Young people were dying and there appeared to be nothing that might change the situation.

3.7.1 Facing a bleak prognosis

Sean described the impact of his AIDS diagnosis:

I really couldn't take it in. I couldn't understand what full blown meant. And the doctors were trying to say, well it's really all to do with World Health Organisation classification. And that to me meant nothing. They couldn't quantify it, they couldn't rationalise it any more than that and I just didn't see, it seemed such a significant step to have taken for them to say, well it's only a matter of statistics. And I'm thinking well no, this is even more of a death sentence. And that just led again to the obvious question well how long do I have left, and at that stage it was three to five years. But three probably, given what I'd gone through with the PCP and the adverse reaction that I took to the antibiotics. I was in the Royal Infirmary I think for about four or five months. And it just felt like this was the end. I'd stopped eating. I'd no appetite at all. I struggled even to think with any clarity about the simplest of things.

This section allows us to see how even the clinicians who were most involved with HIV in its infancy did not always recognise the impact of their interventions and their choice of language. In retrospect, telling people that they were 'full blown' was not at all helpful. The term AIDS is rarely used in Scotland these days, rather the language might focus on describing an opportunistic infection or HIV related illness. Those people who were diagnosed as having AIDS in the 1980s and 90s have that on their medical records regardless of their current state of health. None of the people I know who have an AIDS diagnosis currently has an AIDS defining illness or a CD4 count that is low enough to merit the description.

Annie also talked about the lack of information when she was diagnosed (in October 1985), the resultant paucity of understanding and the impending sense of disaster:

I remember seeing Rock Hudson on the television, and at the time there were some documentaries, but there was nothing about drug users being HIV. It was mostly gay men. I did'nae know nothing. I just thought I was going to die very soon. I probably would'nae see Christmas. I was depressed because every time you turned on the television or the news, people were dying. Rock Hudson, Freddie Mercury and you just think it's going to happen to you too. I was very depressed. I was just waiting to

die. I left the hospital. And that was it. I was just waiting on getting an illness that I wouldn't be able to fight.

Annie echoes the fear that had been absorbed by *Sean*. People were diagnosed and then sent away to self monitor and to wait until an infection arrived that was more than their body could cope with. Both of these people knew friends and neighbours who had been diagnosed and they had watched as other people succumbed to life-threatening illnesses. The impact of that constant reinforcement of the severity of the situation must have been very difficult to manage. The belief that death was just around the corner was exacerbated by the public information campaign that had been initiated by the Government.

Annie again:

I got told two days before my thirtieth birthday. With everything that you read in the papers - and every household in the UK was getting leaflets through the door, saying they'd all be dead soon - and then there were the adverts on the television with all the tombstones falling. And Margaret Thatcher said it was going to affect every household in Great Britain. Although she knew at the time that it was gay men and drug users and prostitutes, but we weren't important to her. We were just scum of the earth. We were'nae worth bothering about.

This quotation is also enlightening for us in seeing the personal impact of a diagnosis. Annie describes herself here as 'scum of the earth', a glimpse of the negativity that people absorbed in the early days. She also gives a good insight into the impact of the tombstone advertisements which were used throughout the UK. That campaign is still remembered for its negativity. Only recently, I met a man who had taken a sexual risk and was worried that he had contracted HIV. His fear was extreme and I eventually realised that the depth of his fear was directly related to his having seen and absorbed the messages from that campaign. He was convinced that an HIV diagnosis would be a death sentence even when given clear information about the way that our knowledge and access to effective treatment has progressed.

People who had been diagnosed in the 1980s found it very difficult to access appropriate support or reliable information. The clinicians were in a fast-changing environment but had nothing concrete to offer at that stage. The voluntary sector agencies that would eventually emerge and offer specialist

support were not yet in existence. The fear of stigma stopped people from talking to friends; isolation with the diagnosis was a real problem. Annie remembers:

You could phone up the Samaritans which I remember I did one night, but the person didn't know anything about the AIDS virus. I think that the person that I spoke to they were just about crying.

3.7.2 Moving from active treatment to palliative care

Dr. Scott spoke about supporting patients to make the transition from treatment to palliative care:

We got AZT in '87 and it didn't make a massive difference to be honest, it became rapidly clear that it was purely temporary and it would buy people a few months but not much more.⁴² So it was still inevitably fatal was the expectation. So giving a diagnosis was, I'm very sorry you've got a terminal illness. You're gonna die. We'll do our level best to keep you as healthy as we possibly can. There will come a point where that will get increasingly difficult and your symptoms will become harder to manage and we move over to palliative care. We wouldn't have the conversation in quite such blunt terms, but that essentially is what you were doing. So it was a preparation for death. Hopefully with a reasonable kind of bit in between.

For example, I always remember one patient whose lifetime ambition was to go to the Taj Mahal. So he came in with pneumocystis carinii pneumonia, got over that, was put on treatment and we basically said now's the time to go. And he went. And he saw the sunrise over the Taj Mahal and came back and said, I have achieved my life's ambition. Which was really really nice. And then he died. He was in remission for a year, possibly even two, but he eventually got CMV retinitis.

Dr. Mike Jones was working in the Infectious Diseases Unit at the same time:

Within a year or two after starting the [specialist HIV] clinic we were starting to get people dying. So the first deaths as far as I recall started to accumulate three to five years later. Some people went downhill very quickly and it rapidly became apparent that this was, well it was already known of course from the American experience, that it was a lethal problem. And clearly the interventions made virtually no difference. So it was actually supporting people who were vulnerable anyway because of the background experience which underlay their involvement, particularly with intravenous drug use. Supporting people who were facing a potentially lethal disease, were living with this thing hanging over them, was I think, very personally demanding. And the other thing was the lifestyle issues. And particularly the big kind of major personal learning

⁴² AZT was the first anti-retroviral drug to be licensed. It became clear very quickly that single drug therapy was not effective

was initially we had quite rigid approaches to the use of methadone. You know you were on a reducing programme and then you'll be off it and then it all started again, and it was making that adjustment from supporting people through the reduction to actually maintaining them on methadone. That was a paradigm shift. It was not something that I naturally warmed to. But I realised that there was absolutely no point in insisting on people coming off methadone if all you do is then propel people back to the most horrendous further intravenous drug use, where they're putting other people at risk and themselves at risk.

I asked him, 'What was it like as a clinician to be faced by this cohort of young people for whom you really had nothing to offer?':

I think it was - well, it's easy to use the words, the patients were challenging. I think it was really difficult and it left those of us who were dealing with this, I think, with a kind of quite profound sense of our inability to actually... We had nothing to offer at that point which was going to make any fundamental difference to the outcome. So we were tinkering at the edges therapeutically. Well obviously Septrin came in quite early on, but we were tinkering at the edges and unable to do anything very much.⁴³ In terms of one's own sense of making a difference it was a very frustrating time.

Dr. Dan Clutterbuck had done a short term job in the Infectious Diseases Unit before he began his career in sexual health and so had experience of both sides of the treatment paradigm:

I was right on the cusp of the change in so much as I started in August '95 and then by June '96 we were putting people on treatment of two drugs. By the end of '96 we were recalling them to add another drug in because we were realising that three drugs were going to make the difference. So I was really just starting right on that cusp. From being in infectious diseases where video was the big thing. So, video messages for kids and lots of palliative care, which I actually really did get a lot out of. A lot of palliative care. A lot of holistic stuff. A lot of talk about can we get you to Christmas. All that sort of stuff. People were really, really at the end of life in lots of cases. To then, a year later, starting to see all these real miraculous recoveries (Clutterbuck, 2015).

Clutterbuck reminds us that much of the intervention with patients was focussed on preparing them and their families for death. The video messages were a significant intervention for many people; they made videos for their children along with memory boxes. Parents had often agreed to long-term foster

⁴³ Septrin is used as a prophylaxis against PCP

placements in order to give the children stability and the videos were a means they used to mitigate rejection by those children.

Clutterbuck's account also allows us to see the movement from the mid 1980s when a diagnosis had no hope associated with it to the situation ten years later when effective treatment began to emerge. All of these clinicians were involved with patients for whom palliative care was the only option. Many of those patients were moved to Milestone for end of life care; those who had adequate support at home could be enabled to die at home. Others died in the hospital. At that time the mainstream hospices did not take in people who were dying from HIV related illness.

3.7.3 Defying the prognosis

Annie spoke about how she has defied her death sentence:

I'm very fortunate that I'm still here because I've seen many people die. Many, many young men and women who never got the chance to take the combination.⁴⁴ I feel I'm fighting their corner too. It's very sad they're no longer here. I think about them a lot. But I'm here and I'm trying to make a difference to my life. I'm 60 years old now. I've lived a lot longer than they bargained for. I never thought I'd be here. I'm healthy. I'm happy. I eat properly. I exercise. I take my combination. I don't take any other drugs. I look after myself. I'm healthier today than I was 25 years ago and I think that's thanks to the support services. Thanks to the combination. And thanks to me for making changes in my life because I didn't want to die. I wanted to live.

For Michael, the lessons learned from his partner's death are still important. He has a very pragmatic approach:

I recognise one day I will die but I think I'll probably make more choice in my route of dying. I want to be pain free, not feel discomfort. Also, knowing that when it comes down to it you don't always get that choice, because things happen. I remember with my partner he'd made definite plans of what he wanted to do but ended up with a brain infection, became demented and so actually he couldn't make decisions about himself. Yes he could do his daily activities but he couldn't make choices for himself. Before my partner died we did have a stash. In other words we were going to have a quick pain-free way to exit, but when it came round to it because he lost his mind he couldn't go down that route because he didn't have the ability to make that decision himself.

⁴⁴ Annie is referring here to the medication (Anti-retroviral therapy) which has transformed the prognosis for people living with HIV. Three or more drugs are taken in combination, hence the colloquial term.

I think once I can't get out, go to the cinema, get out to go down the coast, if I'm stuck and housebound again, I don't know what I'd be like once I'm in that position. Whether I'd find enough solace in reading, things like that. I've seen it with others where they gradually withdraw and then suddenly that's it, you're at their funeral. The people who I thought would be supporting me have also died from other things in terms of cancers etc. I thought my partner's mother, I thought she would be the one nursing me at one point and actually I ended up nursing her. I accept that I may end up being a vegetable or not being able to make those decisions and having a long drawn out death but, unfortunately, that's how life is. I think there's an acceptance, but then the other half of having the cycling accident last year, I'm thinking you can be fit and fine one day and the next day (snaps fingers) that'll be it.

3.7.4 Forward planning

Michael also mentions the way that the men he knew offered to look out for one another:

I remember there was a lot we used to do with the guys from the men's group when we always used to support each other.⁴⁵ In other words if we did kick the bucket, make sure we went home and trash the hard drive and trash the porn stash, trash the toys, (laughs) but I do need to reestablish that sort of link with someone. It's mostly the hard drive and that's password protected.

We see how thoughts about death and its impact are never far away. Michael recognises, even now, that he would like to put arrangements in place that would protect his family from knowledge of his private life. Arrangements to clear a flat are not uncommon. A service user who had fetish equipment in his flat died recently and his Waverley Care friends and support staff cleared his flat before his brother arrived. They were able to ensure that his confidentiality about his sexual preferences was maintained.

The majority of the people amongst whom I have ministered have prepared for their death by making an end of life plan. People have detailed funeral plans, have often put an advanced directive into place and have taken care to have a named next of kin who is apprised of their wishes.⁴⁶

⁴⁵ Michael was a member of 'Juice' a gay men's group that met at Waverley Care Solas.

⁴⁶ In Scottish law it is possible to nominate a named person as next of kin.

3.7.5 Journeying towards death

Having watched his partner and many friends die, Michael is aware of how slow an HIV related death can be:

I feel bad for wishing my partner to die but I just wanted him out of pain. It was January we were called to the death bed and he didn't actually die till May so it was four or five months of just extended death, which actually was quite exhausting.

My experience of journeying with people at the end of their lives resonates with Michael's. I started work at Waverley Care Milestone in May 2000. A woman whom I'll call *Janis* (because we listened to Janis Joplin together) was nearing the end of her life and rarely left her room. Within one or two weeks she had become bedridden. She was frail, she slept much of the time, she had little appetite, and was often too exhausted to communicate. *Janis* was in her early forties. She eventually died in October 2000.

Liz Marr went to work at Milestone after she had gained palliative care experience in an oncology unit. She immediately saw a stark contrast between the situation and support available for the people she'd nursed who had cancer and those who were dying from HIV related illness:

In the oncology unit, it was mostly people who had families around them, mostly had a big support network around them and the work was very much about helping the family come to terms with what was happening: supporting people through really complex treatment, and supporting the wider family to manage while people were so under the weather with it. Having that support network was an important part of their recovery or their treatment pathway (Marr, 2016).

She was shocked when she began her HIV work:

I quickly realised it was completely different from any palliative care experience that I'd had. The comparison between the social network that everybody had, or most people had, in the Western, in the oncology unit. Nobody had anybody around in Milestone and they were much, much younger. So they were all my age, my generation, and some of them had children and partners or ex- partners, but not really any kind of parent figure or aunts and uncles, or a wider family that were stable enough to be able to be that carer or that responsible person. That was quite a big culture shock.

Marr goes on to describe the way that Milestone had adapted to deal with these circumstances:

The first three weeks was really quite difficult. There were quite a lot of deaths, I think seven people died, and didn't have anyone around them apart from Milestone staff or other residents, which felt really different. But what was really lovely was there was such an ethos around: people shouldn't be left on their own. So we sat with them and talked to them - take your books in, take your notes in, do your paperwork and stuff - but they always had somebody with them, which you never had the luxury to do in the Western. I think that had evolved because there wasn't anyone else around.

This quotation shows how the support service at Milestone developed and adapted to meet the needs of the people who were presenting. Expectations within health care settings are often that there is a model within which patients will fit. In this situation, the model evolved in response to the presenting needs of the patient group.

3.7.6 The impact of death

Nigel Cook's partner died from an HIV related illness, as did many of his friends. This is his reflection:

I know several people who were diagnosed and you knew you weren't going to see them for much longer. There were certainly lots of people like that. It was not something pleasant. Losing people, missing their presence and so on is all a big problem. I never expressed it but I maybe handled death in a different way from other people. I get sentimental about the loss of people, and I miss them, but I don't see it as the end of the world, because it's not. I will cry about people, but I have an understanding about death, about moving on and not ending all those expressions. I certainly know there were people who got very emotional about it, particularly if they were losing a partner (Cook, 2016).

In this extract, it is clear that Cook's faith, including his belief in life after death, was instrumental in supporting him to deal with the multiple bereavements that he experienced. However, for many of the service users I have supported, engagement with faith communities was more difficult and problematical. People were often not sure whether church or mosque or temple was for them - would they be accepted, would they be welcomed? Individuals have reported a range of responses in different places. Some churches and synagogues are overtly inclusive, making it apparent in their publicity that they

wish to welcome everyone.⁴⁷ Other communities are clearly more conservative in their approach and some make no attempt at inclusion.⁴⁸ People have absorbed a range of conflicting messages from faith community leaders. Gay men may have heard teaching about God's love, but then have heard that God's love was not for them if they were unable or unwilling to be celibate. Nonetheless, despite many service users' lack of confidence in organised religion, questions of faith were prominent. I was often asked about life after death, about whether there is a connection between people who are alive and their loved ones who have died. People were seeking answers. They searched for spiritual comfort by using resources such as Angel Cards and Tarot cards.⁴⁹ They looked for signs from their loved ones - finding white feathers and hoping for messages relayed by visiting mediums.⁵⁰ This attitude to belief is described by Tony Walter in his paper 'Judgement, myth and hope in life-centred funerals' as a twenty-first century form of hope. He suggests that:

For these younger mourners, often expressing themselves online, the deceased has become an angel. Angels have wings, enabling them to move between heaven and earth, looking after the mourner as 'guardian angel'; if love is eternal, then each lover, the living and the dead requires agency and 'angel' is the perfect afterlife image to express this (Walter, 2016:258).

Walter helps us to identify the underlying need, the requirement for humans to find some source of hope. If people have no religious allegiance and therefore no faith community framework within which to contain their grief, they will seek alternative options in order to meet their need. Access to a chaplain who was embedded within the support services that people trusted enabled the sharing of messages of hope and the symbolic and ritualistic expression of spirituality.

During her interview, Nichola Frith, who describes herself as 'not religious' began to reflect on the impact of her father's recent death on her understanding of the situation that the young people she supports find themselves in:

⁴⁷ See, for instance: www.augustine.org.uk; www.thecathedral.net; www.thecathedral.org.uk

⁴⁸ <http://www.solas-cpc.org/wp/articles/is-christianity-homophobic/>; <http://care.org.uk/our-causes/marriage-and-family/marriage>

⁴⁹ See, for instance: <http://www.angelmessenger.net/free-angel-card-readings/>

⁵⁰ White feathers are often seen as a sign of reassurance that has been sent by a loved one.

I've just been talking about the death of my own dad and how painful that is and how it's made me feel. And how although working with children and young people and they've lost their parents, you never really know or can understand the full impact of that until you actually have your own parent dying. I can't imagine back in these early days how it must have been. Some of these children were just ten years old. Losing one or both of their parents and having to deal with that at a very young age. In all these years I've worked here you're around death a lot. And I've been to many funerals of service users that I've worked with and obviously it does have an impact on you. But it's not the same. You would never realise what it feels like until it happens to you.

Dr. Scott also described the impact of the deaths on him:

We used to get to know the family and friends so well. It was always a really, really strange thing when somebody died - apart from the grief and the sadness at the loss. But what you also lost was 2 or 3 or 4 or 5 depending on the person, really, really close friends. You'd got so close to the family and friends in the lead up to death and then suddenly you don't see them any more. There's loads of folk that I was really close to, that I've never seen again. That was always quite a strange kind of thing.

Jackie Cameron, community outreach worker, discussed how her response to death has changed over the time she has worked at Waverley Care:

I think probably when I first came here I would have thought that's really shocking and people die and I'm really shocked by that. But actually now I think working a lot of the time with the people that you work with, I actually see death as quite a good thing. It's quite a good result for people at the end of the day. And I think some of the service users that I've worked with, they get to a point where death isn't a bad thing for them.

I do feel like that and actually sometimes I actually look at myself and think, are you a really hard-hearted cow, has this made you a hard-hearted cow, this experience of death that you don't feel it's a terrible thing or a bad thing. Or is it just a recognition of that's the way it is. And that's how it is for folk. Very infrequently have I been really, really shocked and terribly saddened. I can think of maybe a couple of occasions working with people where I felt that. But in the main I actually think well the person was kind of hoping for that. So it's not a bad thing (Cameron, 2015).

She also described a situation where a death was unexpected and not straightforward. A woman whom Cameron had worked with for a number of years was resident in Milestone. She had been having treatment for a non-HIV related condition but was not considered to be terminally ill. She was in

Milestone for respite care before returning home. One morning she collapsed and stopped breathing. Staff started CPR and called an ambulance. Cameron takes up the story:

I had such a hands-on role, we got into the ambulance and it was like, can you bag her, can you hold the bag. The paramedic was working on the person and then you go into this big A and E room and that person was there and they're using that big heart start machine. And it's so shocking to see that. I wasn't prepared for that. At all. It was violent. But it was peaceful to see her afterwards.

In this section I have shown how HIV has led people to prepare for their own death and to manage the death of friends and loved ones at an early age.

This chapter has explored the impact on the individuals I interviewed of HIV diagnosis, of HIV related stigma and of being forced to engage with death and bereavement as a result of HIV infection. We have seen examples of the desperation that arose as a response to the situation. It is also clear that there was an impact on clinicians and other professionals working in the field who were left with nothing to offer other than care and kindness.

In the next chapter, we will discuss the experience of living with HIV and, in particular, the reality of living long-term with the virus. We will see that the advent of effective treatment has allowed medical professionals to focus on treatment and to offer hope to their patients. The chapter examines the impact of Waverley Care on its staff and service users, and the opportunities that arose for spiritual care within that environment.

Chapter 4: Living with HIV

In this chapter I will discuss how my research participants have found ways to live with their HIV diagnosis. We will learn about the impact, both positive and negative, for the individuals concerned and we will be helped to understand something of their journeys. The first section will uncover the ways in which people created community for themselves, and will make a comparison with church as an example of the formation of community. This chapter helps us to understand more about the sources of support that were important for the participants and to consider the particular challenges that faced those who were tasked with offering support. We will also understand more about the professionals who are working in this field and the personal choices they have made, seeing that HIV has had an impact on their personal as well as their professional lives.

In line with the style used in chapter three, I will give the date of transcribed material on the first occasion it is used within each section. Pseudonyms appear in italics.

4.1 Creating community

‘My argument is simple. I will suggest [...] that for narratives to flourish there must be a community to hear; that for communities to hear there must be stories which weave together their history, their identity, their politics’ (Plummer, 2004: 87).

4.1.1 A community that takes care of itself

In the first half of the 1980s, when the first infections were being recognised in Edinburgh, there were no organised support services, but the men (and they were mostly men at that stage) who had been diagnosed created their own opportunities for support. Nigel Cook explains:

I had a partner with HIV and he had friends with HIV. There was almost a social network of people with HIV. Like a self-service Body Positive.⁵¹ The nucleus would drop in on each other and make sure they were fine. There was lots of tea drinking going on and people who might have felt all alone weren’t all alone. How much of that was organised, I don’t know. I think a lot of it was spasmodic (Cook, 2016).

⁵¹ Body Positive was a peer support model that emerged in several UK cities.

Cook shows us that from the earliest days of HIV in Edinburgh, people who were living with the virus sought ways to support one another and to ensure that the social isolation that might have been associated with a diagnosis was eradicated. Once voluntary sector services were in place, support and the creation of opportunities to foster peer support, became very important. *Sean* described the impact on him:

It's astounding because I now have a new circle of friends who I can rely on, who I enjoy meeting. We get on very well and these are people who are in the know. They know what I have, they have it as well, they know that some days we won't feel great. And I have to say the quality of people I've met that's the one plus point to being HIV positive. And to have an environment like Milestone as well, with staff who are aware of the disease, who don't judge you. The only place that I've ever felt accepted and on a par with everyone is at Milestone within a group of people, with other service users, it's a commonality I think because of the environment that's fostered at Milestone. You can be caught unguarded, you don't have to watch what you're saying. You don't have to be continually thinking, don't let slip. And to have met some of the people that I've met because of being HIV positive, that has helped me enormously, because there is no judgement there. I've lost count of the number of times when we get together and we all swap stories and each have our different experiences (*Sean*, 2015).

The idea of being with equals, of the reassurance that there will not be discrimination or judgement, was important to *Peter*:

Meeting people through HIV you make connections with them, some people you get on with better than others because that's just what happens. There's also trying to be understanding of people's problems, not necessarily understanding other people's problems because you can't understand them, but understanding the person's suffering. As we all do. And some people, as we see here, have got awful, awful backgrounds.

In some sense HIV can actually be a catalyst, a focus to bring traditions together. So often people are divided about things but something like HIV affects everybody, all communities. It doesn't care what vision or culture you come from. It can be a catalyst to bring faiths together, to bring people of different faiths together (*Peter*, 2015).

Peter reminded me of the way that faith communities are able to bring together people from very different backgrounds and circumstances because they have something fundamental in common. They may not share all of their doctrine, their approaches to worship may be very different but they all have a focus on something transcendental, something that nourishes them spiritually. That

common focus is more important than that which divides them. Similarly, for people living with HIV in Edinburgh, their backgrounds and life experiences were different but the common strand was so important that it made unlikely connections possible.

One of the significant tasks for any HIV agency or clinical service is to ensure that the people who use that service feel safe and comfortable, which ensures that they share their anxieties and are enabled to have the best possible access to the care they need. *Sean* reminds us of the extent to which people become guarded about their language and self-protective in most situations when he says 'You don't have to be continually thinking, don't let slip'. He describes an environment in which people can feel that they are being accepted for who they are rather than the virus they are living with. The next quotation shows us how important peer support can be:

A lot of these people I consider to have a genuine talent for life because they've embraced it, they're just so ballsy. It's just sod you, this is who I am. It (HIV) happens to be part of me but I won't let it define me. I've drawn strength from that. You don't have to share stories necessarily to feel that camaraderie. That's fostered by the environment at Milestone. It's a very non-judgemental environment, a very nurturing environment, and a safe environment.

For all of the negativity that I've faced, here is that other side of the coin, almost juxtaposed with how horrible certain people have been. Or how misguided, I don't know even what you would call it. I don't know whether hatred would be too strong a word. It feels like hatred (*Sean*, 2015).

'It feels like hatred'. We cannot ignore the impact of negative responses on people who are directly affected by HIV; this section allows us to see how a positive environment which nurtures a feeling of safety can make a real difference to the quality of life. All of the service users I interviewed identified a feeling of safety and security as one of the defining elements of the Milestone community. Jackie Cameron was acutely aware of that feeling when she began working as a volunteer:

I was so warmed by the fact that it just seemed to be like, and it still is, it might be a dysfunctional family but it's a big family of staff and service users. It felt very welcoming. Just to come into the organisation. It felt walking in that door that everybody recognised you, they smiled, they

spoke, they had time for you. I was actually a wee bit scared of the service users when I first came here I have to say. Over time it felt more comfortable and I went out there and you got talking to them and they had such amazing stories to tell. And I just listened to these people opening up and just telling you everything that they had (Cameron, 2015).

4.1.2 A community that is church-like

I was with a service user, *Lillian*, at the local hospice. She had just been admitted and was chatting with the nurse. I arrived and was introduced as her chaplain. The nurse then asked, ‘Do you go regularly to church?’ ‘Oh no’ responded *Lillian*, ‘I never go to church. I’m not religious. Milestone’s my church.’⁵²

‘Milestone’s my church’ is a significant statement that encapsulates what Waverley Care services were able to achieve in creating a safe and welcoming environment where people could feel that they were fully being themselves. Those of us who are members of Christian communities would hope that our churches, at their best, offer welcome, sacred space, unconditional regard, non-judgemental listening and support, and an opportunity to experience something of the love of God. John Inge comments in his book *A Christian Theology of Place* that:

[P]laces are inextricably bound up with the communities associated with them, just as churches are inextricably bound up with the Christian communities associated with them. Places then are intrinsic and essential to the building up of human community... (Inge, 2003:125)

This concept of Milestone as church resonated with other service users. I repeated *Lillian’s* statement that Milestone was her church to *Sean*:

I would definitely agree. That’s quite profound. I’ve never felt any negativity there. I’ve never felt excluded in any way. You’re taken at face value and you’re treated with dignity and respect. They afford you a certain dignity that you might not have had living in the community. In the town I grew up in I would have had no dignity at all.

Sean then elaborated on his perception of the impact of ‘Milestone as church’ on him and his attitudes:

⁵² Personal journal August 2015

It's helped me to be less judgemental of people as a whole. It has emphasised in my head and my way of thinking that you have to take people at face value, you can't pre-judge them. It would be terribly wrong to pre-judge. That is reinforced by the people who are up there (Milestone). That feeling of sanctity almost, of the environment that's created there, it would be church like. And if anything were wrong, that is where you would want to be. That's the place you would go to in times of need or times of desperation or sadness or whatever.

When my father died, I felt I was with people who cared. Another service user made something quite extraordinary of my father, when he was an ordinary man. He passed his name to the Buddhists to chant in a temple in Tibet. That touched me and still does. It acknowledges you can be ordinary but you still have a value.

Sean's remarks that Milestone is the place to go in times of need, or desperation or sadness reinforce the idea of Milestone as church. We know that many people turn or return to church at such times in their lives. They do that because there is a connection, however tenuous, and a societal understanding that church is a place to go when things are bad. There is no dedicated chapel or quiet space at Milestone. We create sacred space as and when it is needed and in creative ways. This happens most regularly for funerals. It is still the case that many families do not want HIV to be mentioned at the funeral of their loved one. They have usually kept a secret from the wider family and from neighbours and friends in order to avoid HIV-related stigma. The service at the crematorium or graveside will often be quite general about the person's lifestyle and suitable for a very broad congregation. On the other hand, we have developed a practice of holding very personalised funeral services at Milestone. This will often include an opportunity for friends and other service users to share stories and memories. Given that many of the funerals are for people who contracted their HIV through injecting drug use, the stories are often only suitable in a more private environment, for instance, the sharing of stories about breaking into chemist shops to access drugs, or stories about times when people were using drugs together. These memories are important for the people who were involved with the deceased person at that time, but are clearly not the core material for a funeral homily. They allow us, however, to be true to the person, to honour who they were and how they lived and to recognise them as the person we knew and engaged with. It also allows us to be open about the impact of HIV in that person's life which, in turn, resonates for many of the people who will attend

that funeral. One of the advantages of holding funerals at Milestone is that service users are able to pay their respects and honour the person who has died without attending too many services at the crematorium. This is less important now, but in the late 1990s when there were funerals every week, people found it emotionally draining to attend all of them.

The entrance area of the building is large and open with cupola windows and access from three sides. It is known as the main area and is used for most of the day by the community. The dining tables are at one end and sofas and coffee tables are at the other. There is usually music playing in the background. Groups meet in that space, for example the hobby club where people come together to engage in craft activities, and the community choir which brings together service users, staff, volunteers and members of the local community. It is also a space used for baptisms and funeral services. There is a pool table in the area which is used very regularly by service users. If the coffin is brought into the building when a funeral service is being conducted, we sit it on the pool table.⁵³ It is thus at the centre of community life. I have baptised babies of service users and grandchildren of service users in that same space. I use symbols and music to create a sense of the sacred; the people then create their own sacred space and engage with the sacrament that is being celebrated.

4.1.3 Bringing the ministry of the church into the Waverley Care context

I consider that I managed to exercise my ministry as a priest in the Scottish Episcopal Church despite the fact that the ministry was exercised in an unusual context and within an overtly secular environment - as explored in Chapter 1 (1.7). The majority of my peers who are ordained within the Scottish Episcopal Church will have a ministry that is centred on a church community. They will take responsibility for that worshipping community, meeting the requirements of their ordination by (amongst other duties) preaching, celebrating the Eucharist and caring for the people. For those whose ministry is based within a parish

⁵³ Unfortunately, the presence of the coffin in Milestone is a less regular occurrence in 2016. Most of our funerals are funded by the City of Edinburgh Council as our service users and their families are not in a position to pay. Recent changes to council policy mean that there is no provision for the coffin to be taken anywhere other than the crematorium or cemetery. This is a real loss for people.

setting, there are clear expectations and commitments which enable the life of the community. For instance, there is a Canonical requirement for a celebration of the Eucharist every Sunday, on the Great Festivals and on Ash Wednesday (Canon 22: para 6). These regular opportunities for the community to gather enable that community to form into something that is more than the sum of its parts, to become the Body of Christ in that place. My task as chaplain within a secular agency was to find a way to enable people to become a community despite the fact that the 'usual' tools that might enable that community were not available to me. I never celebrated the Eucharist in Milestone. I heard confessions, I found opportunities to share something of the faith and I made significant efforts to care for the people.

One of the distinguishing features of my chaplaincy, setting it apart from, for example, a support worker role, was that I was obliged by virtue of vows made at ordination to care for the people.⁵⁴ The requirement is not simply to find a way to offer support and to encourage them to manage their lives better, but to *care* for them, to show something of God's love to the people amongst whom I ministered, regardless of whether they had a belief in that God or not. That requirement meant that my engagement with people focused on their care, and, in particular, on their spiritual and psychological care rather than their physical or practical needs.

Faith traditions perceive themselves to have a responsibility to teach, to encourage ethical and moral discussion, to share their ideas and their understanding of the numinous. There were many opportunities to share in that way. Service users would regularly ask questions, often arising from childhood Sunday School teaching that they were now beginning to question. There was concern about heaven and hell and the existence, or not, of purgatory. I encouraged people to think about how they lived their lives and the choices they made rather than the dogma they had absorbed from church teaching. Lord Jonathan Sacks has said that it is not necessary to be religious to be moral, but it helps (Sacks, 2013). I found that it helped in making the conversations about

⁵⁴ At ordination the presbyter is sent out with the following instructions from the Bishop: 'Be a faithful steward of the mysteries of God; proclaim God's word, declare God's forgiveness; celebrate the sacraments; care for God's people. (Scottish Ordinal, 2006:17)

moral and ethical issues possible; people expected that I would be interested in such conversations and often anticipated that I would have something to offer.

Peter offered a reflection on the teaching aspect of faith communities from his Buddhist perspective:

We've all heard the word Guru, but all that means is a teacher. A teacher doesn't have to be a person it can be a thing. Anything that teaches you. And HIV itself can be a guru. It can be a teacher. So, if I didn't have HIV I wouldn't be in this situation, I wouldn't be meeting the people I meet. I wouldn't have interactions with people I meet so it's taken me in a direction. In situations for me, how I react to that is up to me. It is a teacher, has been teaching because it's made me think about the virus, it's made me see life in a certain way, it's made me learn things I might not have learned otherwise and to see things in different ways (*Peter*, 2015).

The suggestion that HIV is a guru seems, to me, to be significant. In this section, we have seen that people changed as a result of their HIV diagnosis. They changed their friends, they changed their attitudes and they found themselves forming a community, becoming the body of Christ (regardless of the fact that they would probably not use that phraseology) in Milestone at that time.

4.2 Unconditional support

Annie discussed the experience of feeling unconditionally supported and by so doing introduced another faith community theme, that of hope:

I don't think I'd be here if I didn't have some of the support. Because most of us that are HIV were depressed, so the support services being there it was somewhere for you to go. It was somewhere where you could talk to somebody who wasn't going to judge you, who wasn't going to look down on you. And who had a bit more information than you did. Talking to somebody about how you felt and about your hopes and about your fears, and just somebody who understood where you were coming from, made a big difference (*Annie*, 2016).

Hope is a theme that was important for *Sean*. After my redundancy was announced, he said that the biggest loss to the agency would be the loss of hope. He described to me how he felt that the hope I brought from my faith community background was distinctive:

It's about trust and hope. You offer quite a clear hope; it's not a false hope, it's very real. It's not always what you say but the emotion that is created. You look after everyone (*Sean*, 2016).

It seems that here *Sean* is describing the experience of being ministered to, being shown something of God's care and love for all of His people.

For *Astrid* there is a suggestion of transformation:

I could have won the lottery and become that really rich person that has no friends. I could be the person that's sitting in the rain begging because of circumstances that have been beyond my control. So it has made me really aware that I just take people where they are, and I would love to see the person I would have been actually if this hadn't shaped me, because there's absolutely no question that it's shaped me (Astrid, 2015).

In these remarks, *Astrid* recognises that HIV has helped to form her into the person she has become. It has made her more aware of other people, more interested in them. In this quotation, she helps us to think about Christ-centred values rather than societal values. She reminds me that if we have made a commitment to follow Christ, we have made a commitment to accept people as they are, to recognise that it is not for us to make judgements. She is referring to something far more profound than worldly riches or an accumulation of goods. Rather, she is directing us towards what St. Paul described as 'the unfathomable wealth of Christ' (Ephesians 3:8). This is a values base that is grounded in Gospel principles.

Michael reminds us that communities are about making positive connections with other people:

In Milestone when people were dying all I remember is the parties and the good times, the good company, the good conversation (Michael, 2015).

Michael is describing something very important here. For men of his generation, there was a succession of deaths and funerals and it would have been very easy for the men who were still alive to become depressed and despairing. After all, they thought that they would be next. The ability to create an environment where people could party, where they could spend quality time with people who cared about them, made a significant difference to the quality of the final months of their lives.

4.3 HIV and relationships

The impact on relationships and the question about whether an intimate relationship would ever be possible was significant for some of my participants. Over the years, many of the conversations I have had with service users have focussed on relationships and whether people would ever find someone who would be happy to knowingly enter into a relationship with someone who was living with HIV. That situation has changed considerably as the efficacy of treatment has improved. We now know that people who are stable on their HIV treatment and have an undetectable viral load (measure of HIV virus in the bloodstream) are unlikely to be infectious.⁵⁵ There are now dating sites for people who are living with HIV and some of the dating apps for men who have sex with men allow the option for men to disclose their HIV status.⁵⁶

However, that was not the situation in the early days and an HIV diagnosis almost always had a significant impact on a person's relationship. *Sean* was unable to reconcile the risks of having sex with his partner after his diagnosis. His partner sought sexual relationships elsewhere; meanwhile *Sean* was referred for specialist help:

I think there were occasions where he [*Sean's* partner] sought sex elsewhere but it wasn't often. I never asked. I didn't want to know but I'm certain it took place. I never held it against him. But equally I thought I couldn't share him with anybody else. If he did meet someone, or if he decided he wanted us to remain together but have a life of his own, I don't know what I would have done. It got to the significant stage that I was referred to see the archetypal nutty professor. It was held in the bowels of the Royal Infirmary in a very small room with a window that ran only along the top with bars. And when we reached our second session he started referring to my wife, and I thought you've never read those notes. And eventually I said to him, 'Look I don't have a wife. It's a male partner that I have'. And I went back to Sandy McMillan [HIV consultant] and said, 'that was a waste of time'. So I was then referred to the Royal Ed [Royal Edinburgh, psychiatric hospital] and I saw a doctor and he prescribed testosterone pills which I wasn't keen on. I persevered. I tried and I had attempted to say to him it's not the actual physical, it all works, it's not the physical side of it, it's the mental side. But he was of the opinion if he could bolster the physical side I was going

⁵⁵ See for example, Bernard, Edwin. 2008 <http://www.aidsmap.com/Swiss-experts-say-individuals-with-undetectable-viral-load-and-no-STI-cannot-transmit-HIV-during-sex/page/1429357/>

⁵⁶ See for example, www.hivdatingsites.biz

to pounce on [my partner] at every opportunity - which didn't happen. It just didn't happen. And by that stage I gave up. I just gave up. To his credit, we remained with each other for five or six years. I think he did have one-off liaisons but very few. I couldn't hold it against him because I was denying him a very important part of a relationship. We enjoyed all other aspects of our life. Except this one.

I asked *Sean* about the impact on him of the decision he had made to deny himself a healthy sex life:

I was quite happy to forego. I must have been. I think it was so imprinted on my brain that I could pass this on to anybody so it didn't - well it wouldn't have occurred to me when I was in the relationship in any event. Afterwards, the very few people that I did have liaisons with, there was no one that mattered as much as him. I was always very upfront, it didn't always win favour with people. And sometimes you could have had a perfectly civilised chat at the bar or whatever and the person excuses themselves to go to the toilet and half an hour later you're still sitting there.

We see here that HIV had a negative impact on *Sean* and his partner; it brought unwanted changes into their lives. When I asked *Sean* how those experiences made him feel, he disclosed some very deep feelings:

Very hurt. Because I had shared information with them. I had given them a heads up that I didn't necessarily have to. It made me feel that I wasn't accepted within a circle of people. It made me feel, unclean's a bit, sounds a bit dramatic. I had to say to myself they weren't worth it in the end but you can only say that so often. It did have an effect.

Astrid was a young single parent who had no idea which way to turn:

Overriding the whole thing was the feeling of loneliness because I didn't want to get involved with anyone. I was so scared. I thought, people are going to find out and then I'm going to get eggs flung at my door. Things are going to happen to me that are going to scare my son.

She met a man through friends who organised a blind date:

I met this guy and he ticked all the boxes, he was a minister's son, he had a decent job, he was terribly well spoken, I was like tick, tick, tick, tick, however I'm not gonna tell him. I can't tell him. He'll just think that I'm filthy. And my dad used to say, 'You're nothing but a single parent scrounger'. But I thought, well you know what, you've been on your own for so long, take a chance. And I took a chance and I told him and he was fine with it, partly I think because he was quite naive and he didn't know much about it. So rather than elaborate on it I just left it there and he, I think, thought it was much like having diabetes or something. I didn't educate him about it. And I thought, well OK here's somebody that's OK about it because they don't seem to know much about it, so I'm not going to educate them about it, but you know they've accepted me. They like

me, they love me, they want to marry me. So I got married and I remember standing at the door of the church and thinking, I don't love this guy. I don't love this guy. I'm only marrying this guy because he's the first guy I've met that I've told that's said that's fine. One of the reasons I did marry him was that he didn't want children. And I thought that's good because I couldn't have [more] children at this point.

These two accounts are supported by many stories that I have been told over the years. Time and again, people have told me that they have no choice but to be single because 'no-one will want me with *this*'. Milestone has been the catalyst for numerous sexual encounters and some relationships over the years, presumably because the HIV question did not arise and people were simply free to decide whether or not they wanted to get together.

4.4 Personal determination

One theme that emerged from the research was the determination and resilience shown by the participants. It is, of course, not possible to say whether that personal resilience has had an impact on the outcome for these people. It is, however, possible to see within their accounts the commitment that each of them made to their own recovery. *Astrid* described how she made a promise to herself immediately after her son's birth:

I'm now a mum and I'm not going to die and he's not going to die. I was a great mum. I really engaged. I thought, if this child is going to lose me, hopefully he won't, but I'm going to make sure he has good memories. I always set little goals, so by the time he was two we would have done x, y and z. If I made it by the time he went to nursery we would have done this list of things. They were always saying to me, you're such a great mum. You're always doing things with this little one. And I knew why (*Astrid*, 2015).

In chapter three, *Astrid* described how she avoided having meaningful contact with other people (3.6) and this extract shows how that decision impacted on her daily life. She was perceived as a fully engaged parent whose focus was on her child. Only she knew the reasons behind her behaviour. She has described to me how challenging it was to maintain that lifestyle, especially as she often felt unwell. It is important to note here the secrecy which defined her interactions with people and the resultant need for her to be completely self-sufficient in her life as a single parent.

Michael spoke about his attitude to his health and recovery:

I was feeling tired, fatigued etcetera but I don't think I ever got to the point when I thought I'm ready to check out yet. I think I always had a fair amount of drive. I always think I had sort of self determination. Yes I had low periods, I had extremely low periods after my partner's death, where I was thinking self harm and suicidal thoughts but I just was missing him, it wasn't about my health, my physical health. That was more about my mental health at that time but I think I got to a certain point where I didn't have that strength to self-harm. I couldn't do it. I couldn't do it to my mum, I couldn't do it to others. And I think you have to be quite strong to take your own life and to be honest I wasn't that strong.

(Laughs)

There's things I like doing. Getting out. Going to the cinema, reading. I wasn't someone who goes and shuts the door and shuts the world out ... Now they talk about self-management skills but I think I had those, that sort of self-awareness that I have to do things I can't just shut myself off from the world. I had family and I also had inherited a mother-in-law after my partner had died. We hadn't married or anything but she became my mother-in-law and she was a main determinate going to visit her and doing things for her.

Michael's reference to self-management links with some of the current work and inputs that are offered to people living with HIV.⁵⁷ These programmes aim to resource people to live with their HIV in such a way that it does not interfere with everyday life. They are taught a range of coping strategies, encouraged to find ways to communicate about their HIV when that is necessary and enabled to look towards a meaningful future. Those are tasks that Michael was able to manage for himself. He found the motivation and the incentives to take control of his life.

Many people who are living with HIV need specialist support to reach the level of assuredness that Michael has achieved. I suggest that is related to HIV stigma. People have heard so many negative messages and are so anxious that they will be vilified if they disclose their HIV status that they disable themselves and stagnate.

Contrast that with, for example, the experiences of people who are living with cancer whose lives are often eased because they have been able to speak openly

⁵⁷ See, for example: <http://patienteducation.stanford.edu/programs/psmp.html> and <http://www.livingwellcic.com/what-we-do/hiv-services/positive-self-management-programme/>

about their diagnosis. Bill Kirkpatrick in his 1988 work *AIDS Sharing the Pain* makes a point that is still relevant today:

To die of cancer is to die surrounded, in most instances, with the compassion of love's enfoldingness. However, to die through being infected with the HIV virus, transmitted as it is through bodily fluids, especially semen and blood, is to die, in many instances, involved in one's own fears of being unwanted, of being a nobody, of being a leper (Kirkpatrick, 1988: 62).

I know someone who died very recently, in her late forties, from a brain tumour. She was able to maintain a blog and to share, very openly, the impact of changes in her health. My friend, Debbie, discussed openly how she felt about the physical changes to her body and the way she was able to use humour to deal with them:

[T]he last few months have seen pretty devastating changes in my body. And suddenly, it became an ENORMOUS thing. I've gained about 3 stones in weight over not many more months. That loss of control has felt alarming, uncomfortable (struggling to climb stairs, etc.) but - the but I didn't expect - deeply, irrationally, shaming. I've wanted to hide my body from everyone. Even my nearest and dearest. Even myself. Tried to pretend I'm fine with it, but winced being photographed. And of course it's a whole package - bald as a coot, red bloated cheeks, puffed up neck, eyes becoming swollen over and faded. I could go on. Most people wouldn't find that easy, I know. But I had no way of anticipating how drastically upsetting I've found it. Not been able to think through and be honest about it. New territory indeed.

I suppose my means of coping - not consciously, but that's what it looks like - was to try and make it the subject of humour. 'If I get in there first, they'll see that I realise how bad I look, but that I'm coping with it fine'. And that's a good strategy in some ways, because there are funny aspects to it. But not as a means of self protection.⁵⁸

The blog posts and ability to discuss the ramifications of her changing body made Debbie's life considerably more manageable. I imagine that had *Astrid*, for instance, been able to share openly and honestly she would have managed her life more easily. In fact, the strain of maintaining a positive persona and being stridently determined has had a lasting impact:

I am known to be really, really stubborn. I am aware I've been really, really determined, I've come out the other side I feel, but the determination needs to soften because sometimes I can be far too

⁵⁸ Debbie Peatman. Reprinted with permission. Accessed from: http://debbiepeatman.blogspot.co.uk/2016_01_01_archive.html

stubborn. And it can be detrimental. I can be really stubborn and if I don't want to do something it's just a no and that's it. So I'm working on that. I used to be, 'No, I'm not doing it, shutters down', because that's how I survived. It was just I felt as if I'd gone through my life just shutters slamming. I can almost hear them. Metal shutters. Bang. Bang. Bang. I'm in this relationship that I've been in for four years and it's had its ups and downs, and a lot of them I can see now are just because of my stubbornness.

A few days after she shared these thoughts, *Astrid* came back to me. The discussion had led her to reflect on her need to be in control. We discussed the lack of control over the virus, the impact of living with a blood-borne virus that cannot be seen or felt but has an impact on every aspect of your being and your life. For *Astrid*, there was a moment of revelation when she recognised that some of her behaviour was directly related to her HIV diagnosis:

I have to force myself to leave things untidy. I couldn't even leave for work in the morning without leaving everything immaculate. So that when I came home it was, it was all in control. It sounds like a really organised woman but it's more than that. My dad was very controlling and I think that's probably been learned behaviour as well as behaviour that's been a result of having HIV, and not being able to have any control over that. So I think the two combined, I mean it's a double whammy. I got a bit obsessed with vacuuming my house and tidying and keeping everything just so. To the point where, and it's quite embarrassing to say this actually, but to the point where at one point I obviously was suffering from depression and I didn't know it. I remember looking around and I saw cobwebs or a cobweb on my ceiling, and I looked and I thought this room needs painted and I just sunk down in the floor and I thought I can't cope any more. This is too much. And it wasn't the cobweb, it felt as if it just was everything.

Astrid then went on to talk about the change in her response and her ability to tolerate some degree of disorder:

I think it's because of the length of my diagnosis and beating it for so long. I kind of feel like I've not beaten it but I've met it head on and I'm walking with it now. It's not overwhelming me it doesn't get me down any more. I just take the tablets and get on with my life now. So it feels as if it's just there, it's something that walks alongside me. It's strange 'cos it doesn't actually feel like, I said I wanted to remove it and pull it out. I don't feel that any more. I just feel like it's there, it's been with me for thirty years, we've had our ups and downs but it's just there.

Sean also spoke about his own sense of taking control. He had been in hospital for several months and was very unwell:

There came a point in the middle of the night and it just suddenly came into my head, you're going to die if you don't fight this. And it was such a significant occurrence that I can remember it with great clarity.

It was a determination. It was a determination not to let it win. It was a determination to change whatever course was going to happen. I just thought this is serious, this is really serious what's happening to me. I have to fight this if I'm going to have any chance any continuance at all to make even the three years far less the five. And I had worthwhile things in my life that I considered, I wanted to fight for. The relationship with my parents and the relationship with my partner. I was fortunate to have these things and it just gave me a huge incentive to just single-mindedly say right I'm going to do this. I'm going to do whatever it takes. But it was very, very significant. As I say it was in the dead of night and it was a sort of melee, a general melee within my head anyway that that was such a significant thought. And it was the only thought at that time. And it was just this I have to fight this. I have to. Or I'm going to pass away. Very, very significant. It's just one of those moments that you never forget. Just one of these things that happen in your life and it never leaves you.

I think it's given me a belief that you can fight. You can. It makes a difference if you do. Whilst other things have happened along the way since then, I can't off the top of my head think of anything as serious as that. But I've always had this sort of reserve in my tank if you like. There may come a stage where it won't work but I'm not going to think about that because it's worked for me in the past. So I just invest a belief in that to carry that with me. It's just pure resolve. Because it's worked in the past there's no reason why it shouldn't in the future. There will come a time when it won't but that's going to be a long time (laughs).

Michael has a sense that his body was relatively strong and that allowed him to carry on when his friends and lovers were becoming very unwell. This extract also shows the impact of his humour on his ability to cope:

Everyone else seemed to be getting diagnoses of cancer and this and that. I just seemed to be sort of escaping it all. And I just thought that's me, that's my health, that's my immune system. It must be quite strong even though I had no CD4.⁵⁹ I always remember at the time we used to do the thing of the fantasy football league, which was eleven or twelve a side (I'm not a football person). When you got to that number you could do your fantasy football league, in other words the footballer you fancied the most. I think I sort of bounced along that plateau for ages but never really got ill. I never got hospitalised but everyone else was ill.

⁵⁹ CD4 count was the only measure at the time of how well the patient's immune system was coping. Healthy people have CD4 counts that are over 700. Some HIV patients had counts that were in single figures.

4.5 The impact on health and social care professionals and their practice

The clinicians I interviewed all spoke about the difference that HIV made to their clinical practice and the accommodations they found themselves making in order to meet the needs of this patient group.

4.5.1 The challenge of managing drug users who were testing HIV positive

Dr. Philip Welsby worked at the Regional Infectious Diseases Unit (RIDU). He remembers the earliest diagnoses of HIV, when it was not clear what the situation was. The clinic routinely saw people who injected drugs when they contracted associated infections and the clinicians were beginning to suggest to patients that there was a new cause for concern:

The impact on the patients was probably zero to begin with because there had been various panics. Hepatitis B was one. Herpes Simplex was another. Genital herpes. Everybody was going to die with suppurating sores. But nothing happened. The doctors were perceived as pressing the panic button. In the early stages we got HIV positive patients who were perfectly well and none of them had friends who'd died with it. The intravenous drug users, their behaviour was pretty uninhibited, they were pretty aggressive as a bunch, and obviously they were deprived by genes and environment and all that sort of thing, but until people started to drop off and get ill and die, I think there was a perception that this was just yet another [case of] doctors pressing the panic button (Welsby, 2015).

This is an interesting contrast with the situation at the sexual health clinic where gay men were presenting and asking for testing. The injecting drug users who used the infectious diseases clinics had experienced medical scares over the years and they may well have thought that this was just the latest attempt to control their drug use. That perception changed very quickly, as it became apparent that HIV was something to be feared. The primary task for the clinicians at that stage was to ensure that people were as well informed as possible and that the risks of transmission were reduced.

Neil Olley, in his unpublished doctoral thesis '*From Morningside to Muirhouse: towards a local governance of the self in drugs policy*', is clear that the substitute prescribing initiative was an important element in the public health approach to HIV prevention:

Techniques of safer self-responsibilisation are, from the mid-1980s onwards, primarily directed at the management of shared injecting use

rather than the deviance of drug use. HIV prevention did not rely solely on needle provision. ... Non injectable substitute drugs were prescribed not just to attract users to services but also to divert them from injection. Intervention attempted to change not only the way a drug was used but the drug that was taken. (Olley, 2003:115)

Dr. Welsby was involved in substitute prescribing which RIDU introduced at a very early stage:

I think it's true to say there were very few people indulging in heroin substitution prescribing. It wasn't sort of organised. There was no policy. As a group they weren't a very likeable sort of lot. They were involved in crime and one thing and another. Some of them had no chance. Their genes and their environment, it was quite sad. I think actually the medical profession responded in a very mature and sensible way. Basically the philosophy was you were trying to make the best of a bad job.

Olley, in his thesis, references an interview he had with a consultant at RIDU:

The reason I took it on [methadone prescribing] was Don Des Jarlais in June of '86 presented a paper in Paris in which he showed a direct relationship between frequency in injecting and crashing CD4 counts. So for the first time we had evidence, nobody has been able to repeat that work, that said if you carry on injecting you'll go faster (Olley, 2003:128).⁶⁰

The same consultant then described the ridiculous situation he found himself in:

In mid '87 I ran out of [prescription] pads... so when I phoned up and [they] said you can't have any more pads [I said] what do you mean? What am I supposed to do?...

Effectively they were saying if they're not [HIV] positive you can't prescribe for them [addicts] because otherwise why would you be seeing them? I said okay fine and they imposed it. As a consequence for a year you couldn't get drugs unless you were positive...' (Olley, 2003:129)

This excerpt shows us how confused the policies were at that stage. It was known that substitute prescribing reduced injecting behaviour, and that HIV was transmitted through injecting drug use, but fear of being perceived to be giving free drugs interfered with the full introduction of a pragmatic policy.

Dr. Welsby was aware of the challenges that came with a clinic that was primarily used by people who were opiate dependent:

On a personal level I became aware that you had to be really careful about how you handled people. As it happens it becomes, I think on a personal level, how you deal with confrontation, and I had a style which

⁶⁰ Quoted verbatim

actually was able to cope with that. Whereas I think other people found it a lot more difficult. If somebody's being stupid, how do you tell them that? It was a long-term commitment. The problem patients would not go away. If they walked out in temper with one thing and another and said I'm not going to come back here ever again, you knew that six or nine months later there'd be a phone call from the GP - somebody's got some infection.

Dr. Mike Jones was also aware of the challenges that came with offering services to this group of people. He discussed the impact on the management of the clinics and his own clinical practice:

The really interesting thing is the way that HIV care attracted or drew into it and retained a group of people who were prepared to, the term unconditional acceptance is sort of bandied around, and it wasn't really unconditional in the sense that if behaviour became sufficiently appalling that it was no longer tolerable, then the unconditional became very conditional (laughs). One of the remarkable things about this unit, and one of the things that I personally treasure about that particular period was that there were people who were prepared to stick with those who at times were sort of putting fingers up your nose and sort of making life really difficult, were prepared to stick with those individuals and provide a consistent level of care. And it was always both disappointing and reassuring when we had patients who went to other units and were dismissed as junkies. And I felt really disappointed that what we had, which was largely, predominantly, not to regard people in that way, in other places that was happening. I think that there was a remarkable consistency of approach which marked out the unit and a lot of that originally came from Ray [Brett].⁶¹

Dr. Jones offers an example of the ways in which the HIV clinic was a creative centre for medical intervention, offering patient-centred care, when he speaks about taking blood from someone whose veins have been ruined by injecting drug use:

You just look for another way of solving the problem and what seems extraordinary becomes ordinary. The interesting thing now is that certainly before I retired is every so often we'd come across somebody with really difficult veins and I say it's alright you know, God created the external jugular for a purpose.

Jones spoke about the personal satisfaction he found in his work at RIDU.

Despite the challenges, he describes it as a positive experience:

I have absolutely no regrets at all about having said yes when I got the invitation to become involved in the care of people with HIV. I have absolutely no regrets whatsoever about doing that. I consider my, you

⁶¹ Dr Ray Brett was the consultant who first took an interest in HIV at RIDU and who established the specialist unit.

know the fact that I was able to maintain a cohort for nearly thirty years, some were the same people that I started with in 1985. There were a few who I had looked after for that long and I consider it one of the great privileges really of my medical career to be able to do that for that period of time. And to actually see people through or to be with people on their kind of journey. It has been a horrendously difficult journey for many patients, particularly the switch from thinking that they were going to die to realising that they weren't going to die. That's a huge change and the possibility of almost being normal I mean it's a huge change. I'm really glad that I had the opportunity to do that. It's enriched my career but not in the sense of, well it's enriched my experience so it's not as if it's made any significant difference to my career path but it has been something that I have constantly been glad has been there because it's been a very worthwhile experience.

Jones refers here to the difficulty for patients in making the switch from waiting to die to realising that they were going to live. It seems that there was a switch to be made for the clinicians as well. They were released from the frustration of having nothing to offer and waiting for their patients to become unwell and allowed again to be doctors, to offer treatment and hope.

4.5.2 The challenges within sexual health

For the clinicians in the Sexual Health clinic, the challenges were a little different. Dr. Scott explains:

I started in GU [Genito-Urinary] medicine as a junior doctor in 1981. It was totally different to what it is now. We dealt with a lot of genital discharge, so guys with urethral discharge, women with vaginal discharge. We dealt with a lot of warts. And we dealt with a lot of people who had symptoms. And the concept of coming in without symptoms to get checked out to make sure you were OK by and large didn't exist. Or if it did it was a tiny minority. The vast majority of people didn't want to come to the clinic, they only came to the clinic if they absolutely had to and that basically meant they had a problem they wanted solved. It was very much patching people up and sending them on their way.

By 1985, the clinic was regularly seeing cases of HIV. Those patients could not be simply patched up and sent on their way. Their care would potentially be complex and it was assumed that they would die within five years. Dr. Scott argued that they did not need to be referred elsewhere:

I eventually said we can deal with this ourselves. Nobody else knows how to deal with this, no-one's got skills to manage sick people with AIDS because no-one's ever had AIDS before so it's not that they need to go to see a particular doctor. They go and see a doctor who actually builds up

their own experience and learns through trial and error. So we actually started to look after our own patients.

That decision was instrumental in the creation of two HIV clinics in Edinburgh, each developing its own expertise and relationships with its client group. Locally, most of the available resources had been used to target injecting drug users because of the fear of spread into the heterosexual population and sexual health clinics were left as something of a Cinderella service. That had an impact on how Dr. Scott and his colleagues worked:

In the late '80s and early '90s, Edinburgh is still dominated by drug use, heterosexual infections. The interesting thing that happened at that time is it became routine, people came forward to get HIV tests. That was the beginning of the change for GUM clinics from, I only go to the GUM clinic if I've got a problem to, I'll go there to get tested even though I don't have a problem. I'll get tested because I've been at risk. It was in about '91 that we got same day testing recognising that, up till then it was a week to get a result and for some people that was really too long, for all sorts of reasons. Sometimes it was because the risk had been substantial and they really really wanted to know but also it was the anxiety about whatever they had done that was making it very difficult for them to cope. So we started same day tests and we used to run them 3 or 4 days a week. They were really popular. So suddenly we were seeing these waves of asymptomatic people which we'd never done before. That's probably the biggest transformation in terms of the routine sexual health stuff. This idea of you only go there if you have to, to you go there if you've been at risk.

I asked Dr. Scott whether he thought there was a shift in people's understanding of risk:

I think there definitely was. I don't think people in the early '80s had a concept of risk. You just shagged anything that happened to go past and yeah...
Up until then people had just done whatever they wanted to do without really considering the consequences. And HIV made them consider the consequences.

This reflection, that HIV had an impact on young people's assessment of risk is highly significant. Dr. Scott clearly documents the change in the way that sexual health clinics were perceived. Before HIV, those clinics saw people who had symptoms and whom they were able to cure. The arrival of HIV, and in particular of same day testing for HIV, brought in a population of people who realised that they had taken risks. It was no longer possible to have unprotected

sex with strangers and risk nothing more serious than genital warts or gonorrhoea. Sex was suddenly a risky activity that could result in death.

Dr. Clutterbuck commented on the risk factor from a contemporary perspective. HIV is no longer a life threatening condition and so attitudes have changed. He drew a parallel between the risk factors for young gay men in 2016 and for young women:

The only difference between young gay men and the straight guys that I'm seeing in the clinic is that if straight guys go out and stereotypically sow their wild oats, if they have a few female partners and make a few slip-ups for two or three or five years in their teens and twenties, biologically they're going to get away with it. And the only difference between them and the young gay men is that biologically they ain't going to get away with it. Or there's more chance that they won't get away with it. I think I see the parallel between young gay men, particularly if they've got vulnerabilities completely other than being gay, whether it's around diet, or appearance or approval or anything else, the parallel between those and young women's risk of pregnancy gets clearer and clearer. They're such a similar population (Clutterbuck, 2015).

Clutterbuck is suggesting that there is a group of young gay men who are at particular risk, and their risk factors are essentially the same as the factors affecting young women who are at high risk of pregnancy. Young people of either gender, who are more vulnerable for a range of reasons, including a lack of opportunity, are more likely to find that the sexual relationships they have are ones in which they are less able to negotiate safer sex. This is an interesting shift in understanding; HIV of itself is no longer the most significant risk factor, rather the vulnerability of the young person is a defining factor.

The relative lack of resources for HIV clinics in the sexual health arena meant that the clinicians had a more holistic involvement with their patients than their colleagues at RIDU which employed specialist counsellors and nurse specialists.

Dr. Scott described the depth of relationship he would establish with a patient:

You know telling somebody they're HIV positive, that first hour is an astonishing trip because you have to find out everything about that person in order to guide them through, particularly the first few days. Partly because of the stigma, and the [questions of] who am I going to tell, who do I want to tell, do I want to tell anybody. What they don't realise, not surprisingly, is people who know you will know something's gone wrong. So you have to have a story. If it's not the truth, you have to have a story and it's got to be believable. So we need to find out where that's going to happen, so I need to know about relationship, family, friends, work, who you're seeing tonight, who you're seeing tomorrow, what you're

doing at the weekend. OK, what story are we going to tell? Are you going to tell anyone? OK, so what are you going to tell instead? They know you. Yesterday you were bright and happy. You're going to be different the next time you see them so you've got to have an explanation for that. It can't be something you're going to get found out about, so what are you going to say. And if you can't come up with a story then you've got the 'flu for the next week. Until you have got your head around it a bit more so you can put on a face. And so you will find things out about people that they've often never shared with anybody else. Or you will have a picture of their life that nobody else has, because no-one else has had to do that intensive assessment of your life and your surroundings in a highly pressurised situation. And then you've built that picture and you guide them through the first few days but there may well be issues that fall out of that that are going to have to be dealt with further down the line. Or they resurface further down the line. You're so entwined in their lives. Not with everybody, some people sort it out. Quite often it's not the same depth but there are some people with whom you have such a deep relationship because of the story and the complexity of their life, and it's such a privilege that people will share that with you.

It was really important in the early days because you're gonna die and it's going to be horrible so you and I need to, you've got to have faith in me that when it gets really, really tough and unpleasant and I say to you, I think we need to do this, you've got the faith in me to go, OK I accept that we have now moved into palliative care mode. We're not going to do anything more active and we're just going to help you have as peaceful a death as possible. For that to work well, the closer our bond is, the more faith you have in me. Now that's not really the case any more so in that sense I'm probably practising on the basis of something that's outdated.

This extraordinary extract gives a feel for the depth of the care that patients received from Dr. Scott. His patients trusted him because he gave them time and he was truthful with them. They trusted him because he made it his business to learn about the virus and also to learn about them. The relationship with him as their clinician probably had a positive impact on clinic attendance and on compliance with medication - if Dr. Scott says he thinks I should try it, then I'm going to give it a go.

Dr. Clutterbuck described a clinic situation that had much in common with the approach taken by RIDU. There was a great deal of flexibility, simply because the priority was to see people and if they would only be seen on their own terms, then that became the norm:

It's affected everything we do. For one thing we've had an incredibly broad acceptance of people's behaviours and people's attitudes and accepted a lot of things that other aspects of the public sector wouldn't

accept just because of the risk of onward transmission. And it's now a small population, it's only about 20% of the people we look after, but in terms of just very simple things like not attending appointments we've had a virtual absolute tolerance of not attending appointments, whereas the rest of the health service has virtually adopted zero tolerance. That is still a factor and it still colours what we do. So there is a definite difference.

Clutterbuck is now in a consultant post and reflected on the impact on his current role:

It is a really interesting concept when you've got some responsibility for governance, because having the softer boundaries but still having boundaries is quite an art, and I think frankly some of the people that have been less strong than we've had in the department equate it to not having boundaries. And it's not not having boundaries. Sometimes you've got to have quite a lot of clarity and on the occasions when we've run into trouble it's because people confuse having soft boundaries with having no boundaries.

These comments are important, particularly with reference to social workers who are trained to have very sharp boundaries. Tensions can arise between professionals because their training and practice guidelines are different and sometimes contradictory. For example, social workers are trained not to share personal information with their clients, such as information about their families. Dr. Clutterbuck and I have both found that sharing some (carefully managed) information breaks down barriers. In Milestone, service users would meet the children of staff; both Cameron and Marr allude to such encounters.

Clutterbuck also commented on the impact of HIV in the wider field of medicine:

I'm sure that patient activism within HIV has shaped patient involvement in other fields. And that's come from HIV. I don't think there's any question about that. It's so long now that it's been a given for us the shock's over. The only thing that's a bit - I hadn't thought of it in this way before - the only thing that I think is regrettable is that the patient involvement was so strong 20 years ago and it's stigma that's stopped it from progressing further. Because in a way it's fallen behind, and it's because when it actually comes to the crunch of being visible as someone living with HIV, even now there's such a minority of people who've got the balls to do it. It's such a shame.

4.6 Waverley Care and its ethos

A regular topic for discussion within the staff team at Waverley Care was comment on the ethos of the agency and the positive impact that had on the

working environment. That, in turn made it difficult for people to consider leaving for another job. People feared that nowhere else would offer as satisfying and interesting an experience. I would echo that sentiment. I had been a member of a multi-disciplinary team within a voluntary sector agency that had made a radical decision to directly employ someone to offer spiritual care, and much of the ethos and culture of the agency stemmed from that decision.

Nichola Frith described the dilemma she faced in this way:

Over the years I've thought I should really move on and do something else. What keeps me here is that I feel privileged to have worked with the people I've worked with. I've met a lot of amazing children and young folk and their families and other people who use the services who are to me quite inspirational. I do feel now it would be hard to leave. For example, a member of staff that I used to work with left and she went to work in this other team, and she said it was hard because people were very closed and were very judgemental. I would be worried about that because I feel working in a place like Waverley Care you do become very open, you don't have any judgements, there's so many different people from all walks of life use the service. And it's refreshing. I wouldn't want to move somewhere else and feel that I had to be somebody else in my job. That you'd have to not say what you thought about things or you had to keep certain topics, you couldn't speak about certain topics. I'd find that quite restrictive (Frith, 2015).

I asked whether that was in some way about being able to bring her whole self into the job. Her response was as follows:

Definitely. I don't bat an eyelid at anything in here and I've heard lots and lots of stories and you're not fazed by it. It does change you. It definitely does change you. I know from speaking to that last member of staff she always says that 'You're so changed'. You forget that in the outside world, in another sort of land, it's very different.

Because of the type of place it is, because you're working with so many different things - people's sexuality, loss and bereavement, people have been involved in using drugs etc., working with gay men, it's just, like, across the board. I just think it opens you up, and there's no judgements on you. You can be, you can say what you want, you can have an opinion.

I think I've actually really developed and grown myself since I've been here. I was only thirty-one when I started and it's changed me. And I think it's changed me for the good.

Jackie Cameron described her experience:

It's a very difficult place to leave and sometimes I feel a wee bit annoyed with myself at not being able to actually make the break.⁶² It's probably a combination of the people you work with, the members of staff but also the service users and the amazing relationships that you're able to build up with them. Even people that we've lost, they're constantly in my mind. And I think the experiences that you have as well. It can go from one day and you're out shopping with somebody and then a near death, a death experience and that can happen in no time at all. So from that point of view I think working in the voluntary sector you're not going to get that in every single job. It's a very unique environment. I think that [dealing with a death] is where you see the best in the staff as well, because it doesn't matter whatever the issues are with the individuals or whatever. This is the uniqueness of Milestone in particular, how people come together and they're all prepared to do their bit and take their role and be there, and give that person the best possible ending that they can have. Even thinking about the road to death and one person in particular who had dementia and used to wander off and everything like that. The actual teamwork involved in that was amazing.

These extracts evidence the impact of the environment and formation of community that was described by service users (4.1.1) on members of staff. The long-term relationships with their clients, the ability to care and support in a holistic way and the satisfaction of seeing that they were making a difference allowed staff to feel valued and valuable. The funding cuts which resulted in the loss of my role alongside others, has impacted on the staffing levels within the agency. It remains to be seen whether the ethos can be maintained in a climate of austerity and increased pressure to work to outcomes.

4.6.1 The wider impact on staff

Jackie Cameron discussed the impact on her family:

I think I was proud of the fact that all my kids grew up with a sense of compassion and they were always very interested in what I did and what was going on. Occasionally they would come into Solas and things like that. Some of them have been in the car with service users. Do you know, they've remarked on what amazing special people they are. Because I can think of occasions when I've been out with the women's group or my son's been in the car with a couple of ladies on the way back from the women's group. I think it gave them a greater sense of compassion. They always seemed quite proud of the fact that I was associated with working up here. They would always say that.

⁶² Jackie Cameron accepted voluntary redundancy in April 2016 and has joined the 'bank' of staff who cover occasional shifts at Milestone in the event of sickness etc.

Karen Docwra also discussed the impact on her children:

I think it has definitely impacted on the values that I try and instil in my kids. That whole thing about not judging and being understanding of people. They're both hugely proud of what I do. I think they really value what I do (Docwra, 2015).

Liz Marr had similar reflections and also discussed the impact on her approach to parenting:

I've always been proactive in pointing out that because people are different they shouldn't be treated differently. They should be accepted and acknowledge that there's possibly something going on. The other thing is about use of language. The kids go through trends and for a while it was ok to say 'You're so gay' in quite a derogatory way. I would have been like this anyway I think, but the terms that I would have found acceptable before, because of where I'm working, I certainly haven't found it. So when my son and his friends were calling one another gay when they did something stupid, I would always have put a stop to that. They both [her children] are really well rounded people who do have a good sense of what's right and what's wrong. And it takes all sorts of people to build a world. They're more accepting of differences and things.

Here, Marr is recognising that the Waverley Care ethos was in some ways counter-cultural. Service users were always challenged if they made homophobic or racist comments; it was very clear that the expectation within the agency was that people would be respected and treated as equals. Over time, service users began to moderate their choice of language, for example talking about going to the 'local shop' rather than using a derogatory term. Staff learned from service users what they considered to be acceptable or not. The term 'service user' is used because people who use services have found that to be the most acceptable option.

Marr went on to discuss the impact on her children:

I think they're really proud of the fact that I work with complex issues and look after people that don't have a lot of people doing that for them in the community. They think it's a really good thing to do. They're both interested as well in the kinds of difficulties that happen on a day-to-day basis, they find that quite challenging and quite interesting how you manage difficult situations. Working here helps you to cope with all sorts of things, how you manage yourself in a group of people, or how you organise your day, or how you organise your life and how you prioritise. My daughter's gone into politics and I think part of that is because of the whole accepting differences, valuing differences, recognising that people face all sorts of really horrendous things actually on your doorstep. I think

it's helped her to say that she wants to try and make a difference. My son is very interested in why people do things and why people behave in ways that may be different from others, and I think that's because of the exposure they've had to people here.

I remember one service user used to love the kids coming up [to Milestone]. And there was always that [fear], I don't want him mixing with the kids - he was a scary bloke. I remember my son sitting in the car at 9 o'clock at night at the end of my shift and that person jumping at the window at the back seat. You'd think for a kid that'd be really traumatising but he just sat there and went 'hiya'.

Marr perceives that her children have been influenced in their choice of career by their contact with Waverley Care. This is an example of the impact of HIV spreading far beyond those who are directly affected by the virus.

4.7 The Christian influences on HIV care and support

Karen Docwra is an active member of her church. We had a conversation about the way that Waverley Care appears to be grounded in Christian principles although it is not a Christian agency:

That thing of being there for everybody, that whole unconditional support you know. And something I often trot out in discussions with funders is one of the things I feel quite proud about. You've probably heard me say it. The thing I feel proudest about in working for Waverley Care is we don't give up on people. So that whole thing about, yes you might be using drugs in Milestone and you might be asked to leave on account of that, however we're not going to close our doors to you. I think for me that does absolutely reflect the Christian principles that God doesn't give up on us because we mess up. It's why I think Waverley Care has a tremendous amount of integrity as an organisation.

I think the whole thing around acceptance and forgiveness. I suppose it's back to what we were saying before about unconditional acceptance. What it does for me is I see that in action in a way. There's a parallel there I think. If I hear people preach about acceptance and forgiveness, that we're forgiven before we even ask for it, it's such a wonderful principle and I do feel that's a principle at Waverley Care. And I think to ground an organisation in something as profound as that is amazing. It's a hard concept. From a faith point of view it's a hard concept. Partly because a lot of the other preaching seems to fly in the face of it.

Docwra is describing here the fundamental importance of what she perceives to be Christian principles emanating from God's unconditional love for all of His people. I suggest that these are actually faith community principles - all theist religious traditions are underpinned by a theology based in love and compassion.

Helen Mein's experience in Positive Help (which is now a wholly secular agency) echoes some of Docwra's reflections:

There was a new user of the service and a Roman Catholic went to pick her up and drive her to Leith hospital. They stopped at the hospital and she got out to make sure the woman got to the hospital OK. And the young woman threw her arms round her and said, 'thank you for caring'. And in that short journey the volunteer had transmitted the ethos of Positive Help which was not to judge, not to preach, not to be godly, to be accepting, not to be prying. And the woman had felt completely at ease and valued. You can't get better than that (Mein, 2016).

Dr. Jones is a practising Christian and he mentioned the connections for him between his faith and his clinical practice:

I had a model, the fact that Jesus had this approach to people. It didn't matter where they were coming from, what they had done, there's always a way back. And I think that for me personally was really important. I think the other interesting thing was that quite a lot of patients had actually had contact with churches (Jones, 2015).

Dean Fostekew is a priest in the Scottish Episcopal Church and a long-term supporter of Waverley Care. He spoke about the underlying ethos of the agency and its connection with local churches:

In the early days when Waverley Care was not as big as it is now, and didn't have so many support workers, the whole spiritual care was actually very high. A lot of the specialist care for other areas was undertaken by the spiritual care practitioners, be that volunteers, be that the chaplain. That role was quite broad in that small organisation. I think since Waverley Care's grown and diversified and taken on more areas of work and expertise, I think that role of spiritual care's been a bit compartmentalised in a way that it never used to be. It was seen as being integral to everything. It was a holistic approach to care, which was very, very strong with Waverley Care. Also it was very Scottish and it was very Edinburgh in those early days and I think that's why people supported. You could actually see what was needed. People who had been ostracised were brought back in and made to feel welcome. And welcome in congregations, and people were able to come into congregations. And congregations took it as a given. Yes there would be fundraising for Waverley Care and people would give generously. Even now people expect World Aids Day to be some form of church involvement to provide for the spiritual welfare of the individuals. It wasn't about bums on seats in the church, it was the church going out and being with people and saying how can we support you? That was integral in those early days. As Waverley Care grew, the spiritual aspect grew with it. The role of the chaplain was very significant in that and was consulted quite a lot for their objective view on things.

Fostekew re-iterates here the significance of chaplaincy for those who were involved in creating the cultural norms within the agency. David Johnson was Director of Waverley Care from 1994 - 2011 and was instrumental in ensuring that there was a spiritual dimension to the service provision. He identified the need in this way:

I think people have questions all the time that they want to have discussions about and I don't think GPs, specialist doctors or social workers are trained to have those discussions. They're trained to have all sorts of other discussions. They're trained to break bad news, they're trained to talk about difficult issues but none of them are trained to talk about the spiritual dimension (Johnson, 2012).

That quotation shows that the spiritual dimension was an integral part of the services that were offered and was of great importance to the senior management at the time. Johnson understood it in this way:

I think it's that bit about tapping into self worth in a spiritual sense as opposed to psychological stuff that happens. You can do work around self worth and self esteem with different professional hats on, but there's something about worthiness and your core inner being, and this kind of what I think goes on about hedging my bets about what happens next. So they somehow coalesce into something which I don't think anybody else deals with.

Johnson is identifying a gap that would have existed in service provision. Time will tell whether that gap emerges in the newly configured services at Waverley Care. Dean Fostekew understood that the success of the chaplaincy service within Waverley Care was, to a large extent, due to the attitude with which the task was approached:

I think because the church were prepared to say we're not coming in with an agenda, we're coming in to get alongside and work with you. We can offer something that helps you in that holistic approach to wellbeing that you're trying to develop because we've got some skills on the spiritual side. The wellness side. How can we share that and how can we work with you to make the lives of the individual people who call upon your services better? I think Waverley Care were probably surprised at that stage by the church organisations going 'We want to support you. We think what you're doing is fantastic. We're not able to do this ourselves in such a good way. We would like to support you - one charity supporting another in areas that we are both committed to'. At that stage I don't think there was any tension or suspicion of either side, this was a partnership and a respectful partnership of mutual support, trust. Now as there are changes in society and religion has become a bad name for folk, there is a bit of suspicion from the secular side of the churches - 'well

what do they want?'. We don't want anything but to be there alongside God's people.

Fostekew emphasises here the point made at 4.1.3, that the core task for the chaplain was to care for God's people. There is an understanding, especially within Catholic traditions, that the role of the priest can be described as the 'cure (or care) of souls', the *cure animarum*, perceived to be the exercise by the priest of his or her ministry. The decision to make the chaplaincy role redundant has made it difficult to exercise that ministry and to continue to have the cure of souls.

Fostekew offered some reflections on Waverley Care which seem especially pertinent, given the situation that now exists:

Sometimes the humanity gets lost. I think that humanity was why the churches were involved, why there was a chaplain, why spiritual care was seen to be an integral part, because it's an integral part of who we are, of our humanity. Waverley Care were so strong and so hot on that at the beginning, that it was about an individual's humanity and nothing should be neglected. And also things should be offered that people may not have even thought about at that time, that could actually bring them some peace, joy and sometimes some resolution. I can think of one or two folk who have died, but actually died in a much better place mentally and spiritually than they would have done if there hadn't been that spiritual care and chaplain's support. For those who would say 'You'll never see me in a church but don't take my chaplain away'. It was very much 'That's my church I don't go to', and 'That's my priest from a tradition I don't believe in'.

These remarks resonate strongly with the section above that describes Milestone as church. My hope is that it will now become possible to offer a spiritual care ministry to people in Edinburgh in a new way.

In his final remarks, Fostekew suggested that there was a two-way benefit between the church and the HIV sector, that in some ways HIV was a gift to the church:

It hadn't been that many years before that we'd allowed the remarriage of divorcees which was a big challenge. And then we began to look at human relations and seeing good stable positive same-sex relations and the church saying 'How do we respond to this?'. It was the church challenging itself as much as working with people in society. There was a dual thing going on but that experience of working alongside the marginalised was making the Scottish Episcopal Church challenge its whole beliefs of who are God's people? Who is acceptable and who is not?

It made the church wake up. It had been too complacent and thinking that everybody was the same. This sort of 1950s mum, dad, two children. Well it was no longer like that. It might be mum, dad and two children but they might all be HIV positive for whatever reason. And dad might be a man who had sex with men that mum didn't know about. The whole gamut of sexuality began to be explored. Honesty began to seep in. I think that's where gay people became a bit more visible in the church. They didn't have to hide any longer. It was OK to say this is who I am. I think that came from that experience of working with people on the margins.

The observation that HIV has made the church look more openly at human sexuality is highly significant. Faith communities have been forced to have discussions about issues such as condom use and to openly acknowledge that not all sexual activity happens within marriage. In 2016, the Protestant churches in Scotland are almost all actively engaged in discussion about same-sex relationships and same-sex marriage. Decision-making bodies within those churches are engaged in discussions that could lead to significant change in their practice and theology of marriage. The process may have been driven, at least in part, by changes in legislation but the significance of HIV in this area should not be underestimated. HIV forced the churches to talk about sex and human sexuality; those debates have paved the way for more inclusive debate on the nature of marriage. We see that HIV has been a catalyst for change within the churches.

This chapter has explored in some depth the impact of HIV on the people who have been most involved for many years. It has shown that there has been an impact on people's spiritual lives and that they have found ways to form community. I have shown that it was possible to offer an important priestly ministry within a wholly secular setting. The impact on clinical services has been explored and differences noted between the services working with gay men and those catering primarily to injecting drug users. Finally, I look at Waverley Care as an agency, considering its distinctive ethos and the impact it has had on its staff. I consider the influence of the churches on Waverley Care and raise a question about its future direction.

In the final chapter, I will reflect theologically on the material that I have gathered.

Chapter 5: Reflecting theologically on ministry within a secular context

Chapters three and four examine the many ways in which HIV had an impact on the participants in this research. These chapters identify the key themes that emerge from my research, and offer reflection and analysis on them. In this chapter, I adopt a reflexive approach to the subject matter, bringing my personal experiences, my role as an ordained person, and the impact on my spiritual life to the fore.

5.1 A Christian ministry within a secular agency

My HIV ministry was exercised within a wholly secular agency, Waverley Care, where I was tasked with offering pastoral care and finding ways to have an overtly spiritual presence. The agency struggled to name, and at times to understand, my ministry. In chapter one (1.9) I discuss in some depth the range of tasks that I undertook and the way that the role evolved. Each of the job titles I worked to was adequate at the time but, perhaps inevitably, only conveyed a portion of the work. The struggle to find language adequate to describe and name the work is made more difficult by the fact that the role was one that I understood to have emerged from my Christian ministry, a direct response to my understanding of God's call on my life. Each of the expressions of ministry came out of my own faith and calling to serve. There was a clear requirement to be available to people of all faiths and none and a strict injunction against any kind of proselytising. In many ways I was fortunate to find myself in a position where I was able to craft a role that suited my gifts and prior experience.

My personal spiritual journey is grounded in the work and writings of Ignatius of Loyola, a fifteenth century saint who founded the Jesuit religious order and is best known for his 'spiritual exercises'. I undertook ('made') the exercises twenty-five years ago and have participated in Ignatian style retreats on an annual basis since then. The framework within which my spiritual journey has been lived puts a significant emphasis on discernment, on recognising that which draws us towards God as opposed to that which tempts us to turn away. It was

important to me to regularly discern, to the best of my ability, that this was still the ministry to which I was called. Pope Francis, writing in *Amoris Laetitia* describes such reflection as ‘a process of accompaniment and discernment which guides the faithful to an awareness of their situation before God’ (Francis, 2016: para 300). The aim was to ensure, through prayer and listening, that I was where God wanted and needed me to be. I was able to seek support and confirmation for this from my external supervisor, someone with a religious background who was able to supervise my therapeutic work, from my spiritual director who offered space for reflection on my spiritual life and journey and from service users. Feedback, both formal and informal, suggested that the ministry was beneficial and had an intrinsic value. This made dealing with the decision to make the post redundant particularly difficult. I was forced into a new process of discernment and prayer, emerging from circumstances that were not of my choosing and did not appear to me to reflect God’s will.

5.1.1 Expressions of ministry

The expression of ministry that evolved within Waverley Care allows us to understand how many of the elements that are significant within faith communities, (and which may be ways in which those communities define themselves), can be created and honoured within a secular environment. These include: creating community, creating sacred space, recognising sacramental experience and marking significant life events. I will consider these in turn.

5.1.2 Creating community

Community, and the formation of community, is central to the practice of religion. Faith communities gather to worship, to learn about their sacred texts and to pray together. The creation of community is a factor that distinguishes religious adherence from belief. It is possible to be a believer in isolation; engagement with a religion and its doctrine demands more, the communal activity defines the community.

The impact of gathering in one place with a common purpose can be either positive or negative. At its best, the community creates an environment of care and support, a place of safety. At its worst, the same environment can be experienced as judgemental and exclusive.

Oral history evidence at 4.1 shows the importance of community to the people living with HIV whose stories I captured. Individuals from a range of backgrounds and life experiences were drawn together around a common interest - the ability to speak in a safe place about HIV, to share experiences and to seek peer support. From this starting place of shared concern, friendships have developed and confidence has grown. Inevitably, there were people for whom the environment at Milestone proved more difficult. Some people found it difficult to comply with the community guidelines and rules, whilst others found it difficult to spend time in a residential unit with people very different from them.

Clear parallels can be seen with the experience of faith community as described above. Worshipping communities are gathered groups of people who have some shared beliefs and/or experiences but who may have little else in common. Some members of churches, synagogues, mosques and other religious institutions find it impossible to comply with the rules of their community. Some find that being alongside people who are different from them is challenging. Religious institutions manage to bring together disparate groups and to create a safe enough environment for most people. Milestone managed something similar.

5.1.3 Creating sacred space

There is no chapel at Milestone, nor is there a dedicated quiet space. Visitors regularly comment on the atmosphere in the building; most people experience a sense of peace when they enter. Service users will speak about relaxing the moment that they cross the threshold. That is especially true of those who live with their HIV secretly. This is more than an environment that is pleasant and relaxing, it is an environment that invites people to share their vulnerability, to open themselves to the possibility of change. Places of worship are also environments where the possibility of change is acknowledged, perhaps even expected. Simply by offering an appropriate space, opportunities are created for HIV to act as an agent of change.

At times overtly sacred space is created to facilitate spiritual expression, for instance for baptisms, funerals and weddings (see 4.1.2). At those times,

Milestone becomes church (or temple or synagogue) in an overt way. I am reminded of a quotation from Desiderius Erasmus which hung in my office, 'Bidden or not bidden, God is present'.⁶³

5.1.4 Sacramental experience

St. Augustine taught that a sacrament is 'an outward and visible sign of an inward and invisible grace' (Diocese of Westminster, 2016). My experience of ministering within this community was one of being touched, time and again, by grace. Individuals may not have defined themselves as religious and may have lacked theological language. However, they brought an honesty, an openness, a genuine desire to explore the numinous that I have rarely experienced in formal religious settings. There were regular conversations about spiritual matters, in particular about heaven, hell, the soul and prayer. People felt able to ask questions, which in turn led to discussion and learning. They felt able to ask for a blessing, for prayers for loved ones, for a candle to take to their room. Lapsed Roman Catholics would find comfort in rosary beads or holding crosses. The sacramental ministry of the church was not regularly offered, but the sacramental ministry of one to another was a regular feature.

5.1.5 Marking significant life events

Baptism, marriage and funerals took place at Milestone. The starting place for every funeral I planned was 'You can have whatever you want so long as I can give everyone a blessing at the end'. No-one ever decided that they would prefer a different celebrant on that basis. I explained that for my own integrity, giving a blessing allowed me to function as a priest and therefore to have the authority to go ahead with the service. When Milestone was still a hospice and the majority of our deaths occurred in the house, there was a small mortuary on site. Normal practice would be to wash and dress the person in their room, enlisting the help of loved ones where possible. We would play the person's favourite music and talk to them as we worked. When they were ready to be moved to the mortuary, we wheeled them in their bed with their face uncovered. That was important; one of the aims was to normalise death, to take away some of the fear that people might feel and to allow other service

⁶³ Accessed 23:6:2016 <http://www.biographyonline.net/erasmus-quotes/>

users to say goodbye. The person would normally stay in the Milestone mortuary until the day of their funeral when the funeral directors would bring the empty coffin into the building and transfer them. Usually, there was a service at Milestone before the cremation or burial.

Those services at Milestone tried to strike a balance between informality and appropriate reverence. The most important element though was to ensure that it felt as though we were sending off that particular person. It was common for people to put things on the top of the coffin which (as I described at 4.1.2) would usually be in the main area of the building. One memorable time, a man had died in his chair just after his wife had made him a cup of tea. She saved the cup of tea until the funeral and put it on his coffin along with his ‘stash’ tin.⁶⁴ Keeping people in the house also allowed for an eclectic mix of items to go inside the coffin. Cannabis was a regular gift for the ‘journey’, often in the form of a rolled ‘joint’.⁶⁵ One man’s partner gave him a joint, a miniature of whisky and £10 for a bet on the horses! In Milestone there was a candle holder made by a stained glass artist and a candle would be lit when someone died in the house and would not be extinguished until the coffin left the building. The content of the services at Milestone usually included a time for everyone present to share a story about the person who had died. The familiarity with the environment allowed both participation and uncensored contributions. We often heard tales of crimes that had been committed with the person who had died, or explicit references to their personal life.

I always found something to read, usually poetry. I often used resources designed for children’s funerals, as they were very accessible.⁶⁶ Sometimes people had profound experiences, either individually or collectively. One significant example was a funeral that I took in the conservatory. This was a man who was not very well known within the community and it was a small gathering so the more intimate space felt more appropriate. I read the story of

⁶⁴ His store of cannabis

⁶⁵ cannabis cigarette

⁶⁶ See for instance, Dominica, Sister Frances. 1997. *Just my reflection. Helping parents to do things their way when their child dies*. London. Darton, Longman and Todd.

Jonathan Livingston Seagull.⁶⁷ As I began, a few seagulls gathered on the roof of the conservatory. As the story progressed, the seagulls appeared to be acting out the narrative until there was just one seagull left on the roof and he eventually flew away. Most of the people at that funeral were left wondering what had happened and whether they had witnessed something of God.

I rarely led intercessory prayer during a funeral service, but I managed to pray for people nonetheless. This is an example of something I would read that, for me, is prayer but was acceptable for people of all faiths and none:

We trust that beyond absence there is a presence.
 That beyond the pain there can be healing.
 That beyond the brokenness there can be wholeness.
 That beyond the anger there may be peace.
 That beyond the hurting there may be forgiveness.
 That beyond the silence there may be the word.
 That beyond the word there may be understanding.
 That through understanding there is love.

5.1.6 Ministry as mission

An important feature of my ministry was to make overt connections between the faith communities and Waverley Care. There was an educational agenda, for instance seeking to challenge HIV-related stigma and to ensure that HIV was still considered to be relevant for churches and other places of worship. With African communities, where late diagnosis is an issue, there was a task to encourage engagement with testing; experience has shown that faith community leaders can influence testing rates.

One of the creative pieces of work that became an unexpected piece of mission and outreach was the Tartan Ribbon Community Choir. After discussion with a colleague, we made a decision to start a choir at Milestone. We knew that it would not be a viable idea without some support from confident singers. We advertised within two local churches and recruited a core of supporters who were able to offer stability and consistency to the choir. Waverley Care volunteers and staff also joined. Service users were thus enabled to risk joining the choir. A young musician, Rachel Revely, was exploring the question of

⁶⁷ Bach, Richard. 1970. *Jonathan Livingston Seagull*. London. Macmillan.

ordination and offered to be the musical director. She was keen to take on a challenge where she would meet people who were very different from her church choir colleagues. She was changed by the experience - both by her contact with Milestone and its particular ethos and by the transformation she witnessed amongst the service users in the choir. She later wrote about the experience, 'The choir proclaims the sacred and secular good news that love is stronger than anything life can throw at it'.⁶⁸ Within a few weeks it became clear that the choir was the only Waverley Care group which did not differentiate between service users and other members. There was no power imbalance - some of the service users were more confident than some staff and volunteers. The community based choir members did not know who was a volunteer and who was a service user. The task and the challenge were equally difficult and equally fulfilling for everyone.

The choir's first public performance was at Waverley Care's service of thanksgiving to mark its twenty-fifth anniversary. It was held in St Mary's Cathedral in Edinburgh in May 2014. The choir, three months into its existence, sang a traditional spiritual, 'Steal Away' in three parts. The impact on service users was extraordinary. People's confidence was boosted in a way we could not have imagined. Most had never been a member of something that became more than the sum of its parts; they all reported feeling good and proud of themselves.

There was also an impact on the church members who were part of the choir. Most of them had not knowingly had contact with people living with HIV and few of them knew people whose circumstances were very different from their own. The choir broke down barriers, it created opportunities for people to see past their pre-conceived ideas about one another (in both directions) and some friendships began to emerge. The choir performed in churches on a further three occasions. Despite the fact that the majority of choir members were not normally comfortable in a church setting, the fact of their participation in the events made it possible for them to relax in a church setting and to engage fully.

⁶⁸ Email correspondence with the author

The tartan ribbon choir is a good example of mission. Church and voluntary sector came together in a shared activity and both benefitted and grew as a result. The service users were challenged in their ideas of what kind of people go to church and how they might respond to them. They experienced genuine openness and care from people who were strangers but who had chosen not to pass on the other side.⁶⁹ The church members were equally challenged as they recognised how easy it can be to de-personalise people and to have opinions and make judgements based on third-person information about issues rather than first-person knowledge of lived experience.

5.2 The impact on my spiritual journey

During my time at Waverley Care, I found that my personal spiritual journey became more entangled with the ministry. I began to reflect upon the liturgical year through the lens of HIV. In particular, I found that my learning from people living with HIV had a significant impact on my engagement with the Stations of the Cross, a traditional Lenten devotion that follows the journey Jesus made from condemnation by Pontius Pilate to being laid in the tomb by Joseph of Arimathea. I gained a deeper understanding of what it is to be condemned, what it might mean to stumble and fall on the journey and what stripping someone of their clothes and their dignity might feel like. This greater understanding and empathy emerged as I heard individuals' stories, stories such as those which form chapters three and four of this thesis.

5.2.1 Reflection through the lens of the Stations of the Cross

I will not engage here with all fourteen Stations of the Cross, but will comment on a few that are significant. This is a process that has been important to me for a number of years and one which continues to offer challenge and material for reflection.

Jesus is condemned to death

Reflecting on the first Station, Jesus' condemnation by Pilate, I make a connection for myself with the experience people described of receiving a diagnosis. They felt condemned, they knew that nothing would be the same

⁶⁹ Luke 10:30-37

again. The people who were interviewed for this research were diagnosed at a time when that diagnosis was one of terminal illness. The only question was how long they might survive. They looked ahead to a journey of uncertainty and problems; it is not difficult to equate that with the journey that lay ahead for Jesus as he set out on the Via Dolorosa (the 'way of grief'). There was no option in either situation other than to set out on the road ahead. I wonder what the impact is of knowing that there is a difficult and painful way ahead, of feeling that there is no hope, nothing to look forward to, no possibility of a reprieve. I imagine a person weighed down by their diagnosis, feet dragging and gazing intently at the ground. This is a place of absolute despair.

As I reflect further, I am able, through the stories of the medical professionals I interviewed, to reflect on how the experience of sentencing Jesus to crucifixion might have affected Pilate. Like the physicians, he was employed in a role and found himself performing difficult tasks. Like the physicians, he was in a position of authority. The Gospel writers suggest that Pilate would have preferred to save Jesus, but the crowd disagreed.⁷⁰ Pilate found himself in a similar position to the clinicians - he would have chosen a different scenario but that was, ultimately, not in his gift. The impact on the doctor of giving a diagnosis that felt hopeless can be seen at 3.2 when Dr. Scott describes the situation as 'a nightmare'. Pilate washed his hands when he realised that nothing would change, symbolically passing the responsibility to the crowd.⁷¹ In both cases, they had no option but to continue in their role; they had ongoing responsibilities and had to move on. The people who were unable to move on were, of course, those who had been condemned.

Jesus meets his mother

At the fourth Station, where Jesus meets his mother, I find myself reflecting on the impact on families of an HIV diagnosis. I am reminded of the secrecy that is so well described by Nichola Frith at 3.6.5 where she discusses the impact on children of living in a family where one or both parents has HIV, and the extent of the stigma that is experienced by people living with and affected by HIV. I recognise the shame that is associated with condemnation to death by

⁷⁰ Matthew 27:17

⁷¹ Matthew 27:24

crucifixion and see a parallel with a diagnosis of HIV infection, effectively for my interviewees, a condemnation to death by a stigmatised infection. Jesus is traditionally portrayed as embracing his mother at this Station. I assume that there was an element of comfort, that she was able to experience his love for her, that the memory of his touch remained after his death. For people diagnosed with HIV, especially in the days before treatment, there was significant concern for those who would be left. Dr. Clutterbuck refers to people making videos for their children (3.7.2) in an attempt to leave something tangible.

Simon of Cyrene carries the cross

The fifth Station shows Simon of Cyrene helping Jesus to carry his cross. Simon did not volunteer for this task but was chosen from the crowd. He did not intentionally become involved but found himself in that role, a role that has captured popular imagination over the years, making his name synonymous with unconditional support. This Station reminds me that there have been many people who have helped and supported people living with HIV on their journeys. Like Simon, many of them did not choose to travel that particular road, but found themselves in a particular place or role at a particular time and were drawn into the story. For instance, the early hospital consultants at the Infectious Diseases and Sexual Health clinics were on their own career trajectories when HIV emerged and changed things completely. Housing officers who supported drug users, social workers whose work was with women and children who were affected by drug use, community activists who sought to improve the civil rights of gay men, all found themselves directly affected by the HIV virus. Some discovered that they were not comfortable in that work and they found other paths for themselves; some actively chose this road (3.4; 4.6).

Veronica wipes the face of Jesus

The sixth Station depicts Veronica who, by tradition, reached out and wiped the face of Jesus. There are people, for instance the Positive Help volunteers described by Helen Mein in her interview, who actively sought to find ways to help this group of people. She described how the initial cohort of volunteers were all members of faith communities, a good example of the way that people of faith responded to an identified need and were able to make a difference.

The importance of recognising the needs of others is stressed by Pope Benedict in his Encyclical *Deus Caritas Est* when he says

[L]ove of neighbour is a path that leads to the encounter with God, and [that] closing our eyes to our neighbour also blinds us to God (Benedict XVI, 2005:para 16).

Waverley Care staff such as Liz Marr and Jackie Cameron made an active decision to work with HIV, a decision to offer support from their professional backgrounds to this cohort of people. Their motivation may not have been faith-based but the outcome was similar. For Marr in particular, the decision emerged from personal experience within her family (3.6). The parallel with the story of Veronica is the desire to reach out and help, despite that being a counter-cultural action. I imagine that Veronica took a risk by reaching out to Jesus - she could have incurred the wrath of the Roman soldiers. He was dirty and sweaty and bleeding. That did not stop her; she responded to the human being in front of her and, tradition tells that she was rewarded with the imprint of Jesus' face on her cloth. Fabric and its use in memorialisation is important in the narrative about Veronica and it has also been important for people affected by HIV. The NAMES project (2.6) and the Milestone quilt(2.7) are both examples of ways that bereaved loved-ones have used fabric to create something significant that allows them to honour those who have died. We know that people living with HIV in Edinburgh were sometimes dirty and sweaty and their blood was infected. Despite that, those who have chosen to reach out have been rewarded (4.6).

Jesus falls for the third time

This point in the devotion of the Stations seems to have resonance with the struggles that people describe. They speak, time and again, of disappointments, of hospital admissions, of opportunistic infections that they struggled to manage and yet each one managed to pick themselves up and to continue on their journey. I am reminded of the resilience that people display, the sheer determination to struggle through. The narratives in chapter three illustrate this very clearly when we read of times when people felt that they were broken, that the setbacks were relentless and yet they are still alive. The section on mortality (3.7) gives a number of relevant examples.

When the Stations of the Cross are used as a devotion, this Station is often used to encourage participants to 'dig deep', to find the inner resources which will allow them to continue on their journey. I think, in particular, about spiritual struggles, about the times when deepening the engagement with God feels too difficult, too challenging. This Station is one of encouragement in the face of adversity.

Jesus is stripped of his clothes

Clothing offers protection both physically and emotionally. Clothing can keep us safe, for instance by protecting our skin, and it can also help us to feel emotionally safe by creating a barrier between us and the world around us. Stripping can be used as a form of humiliation and a means to degrade people. Shame is often associated with our bodies and we cover them with clothing to allay that shame. Jesus was stripped of his clothes, stripped of his dignity.

I think about the way that dignity has been stripped from infected people, the interventions that have left them feeling that every aspect of their lives was open to scrutiny, the assumption that conversations that would seem intrusive in other contexts were appropriate. For instance, gay men living with HIV are routinely asked about the number of sexual partners they have had in the previous few weeks or months, the type of sex that they have had and whether they have managed to negotiate safer sexual practice on every occasion. Drug users would be asked about their sex lives, about the disposal of injecting equipment, about disclosure within their families. People were not invited to share personal information, they were expected to do so.

These reflections have allowed me to go deeper in my own journey with God. They have given me the opportunity to make an overt connection between my ministry at Waverley Care and my spiritual journey. I feel that I am more able to understand the impact of the events of Holy Week; in turn that has allowed me to craft reflections and prayers that have supported others to broaden their understanding and perspective.

5.3 Locating the ministry within an ecclesial framework

The Scottish Episcopal Church is keen to emphasise the ministry of all believers, making it clear that all followers of Jesus Christ are called to ministry, and that some are called to particular ministries.⁷² Paul Avis defines ministry as ‘work for the church that is recognised by the church’ (Avis, 1999:7). The work I did at Waverley Care was recognised by the church; my license from the Bishop was to be chaplain to people living with HIV and the Province made a financial contribution towards the costs of my employment. Defining that ministry has, as we have seen, not been an easy task. I will now show how it has a place within the broader ministry of the church.

Authorised ministry within the Scottish Episcopal Church may be to Lay Readership, a ministry with a focus on preaching and leading non-Eucharistic worship, or to one of the three-fold orders of ordained ministry, namely deacon, priest and bishop. It is an Episcopal church and therefore all ordinations are conducted by a bishop who is understood to be in the line of apostolic succession from St. Peter. I am ordained as a priest within my church. Ordination is never directly to the priesthood. There is a time (usually one year) when the minister is a transitional deacon, that is an ordained deacon within the church who serves in that role before consideration is made by the bishop as to whether the individual is called to ministry as a priest (described in the ordinal as presbyter) in God’s church. The understanding within our church is that those ordained as presbyters continue to hold the office of deacon throughout their ministry. There are also those whose calling is to a distinctive diaconate and they exercise ministry as a deacon throughout the time of their service to the church.

The distinctive feature of a diaconal ministry is that it has an outward focus. Deacons are often described as standing at the door of the church and looking out. In other words, they are tasked with ensuring that the worshipping community is engaged with the wider community, that there is a tangible connection between what happens within the church building and what happens outwith it. Priestly ministry is distinguished by its function as leader of a

⁷² 1 Corinthians 12:4-13

community (usually a church), by presiding at the Eucharist, and having the church's authority to bless and to confirm God's forgiveness.

5.3.1 The diaconal nature of the ministry at Waverley Care

The ministry I exercised at Waverley Care was an expression of both diaconal and priestly calling. Its diaconal nature becomes clear when we read this section from the Scottish Ordinal:

In a distinctive way deacons are a sign of that humility which marks all service offered in the name of Christ. They bear witness to the Lord who laid aside all claims of dignity, assumed the nature of a slave and accepted death on a cross. In the name of the Church, deacons care for those in need, serving God and the world after the pattern of Christ (Scottish Ordinal 1984:18).

The ministry was, indeed, one of service. Its focus was on people living with HIV and, as described throughout this thesis, primarily those people living with HIV who were socially and societally excluded. Many churches would feel a desire and perhaps a responsibility to offer charity and support to people whose circumstances leave them marginalised. The example given throughout his ministry by Jesus suggests that we should have a concern for those who are not treated well within our communities. It is not always easy for churches to express their concern and care in a way that is readily acceptable to the people in need. There have been many examples of well-intended initiatives that have left people feeling more excluded. For example, attempts to offer food to hungry and homeless people are welcomed but do not always leave people feeling valued or honoured.

The aim of my ministry was to meet the service users where and how they were and to simply be alongside them. The call was to serve, to follow in the footsteps of Our Lord who washed his disciples' feet. The starting place for my ministry was not that everyone would believe, or would come to belief, but a deep desire that I would find ways to give people a glimpse of God's love in their lives. That was challenging in a secular agency where God talk was not always welcomed. It was a useful reminder that people are more likely to encounter God in our actions than in our words.

5.3.2 The priestly nature of the ministry at Waverley Care

I described in the paragraphs above the ways in which this ministry was an expression of diaconal calling. At the same time, there was a priestly expression. This was most often expressed in the ministries of forgiveness and of blessing. Many service users were lapsed Roman Catholics. There is a strong Catholic representation within the more deprived areas of our city, areas where Irish labourers were housed and rehoused and from where many of the service users came. Those people often held in great store the traditions of making confession and seeking forgiveness through the church. I heard confessions, both formally and informally and was able on many occasions to reassure people that God had forgiven them. Often the problem was that they needed to forgive themselves for the sins they had committed, some of which were very serious.

There was also a place for the exercise of leadership and authority. I was aware that as an ordained person, my words were taken seriously and I needed to be careful about what I said and how I worded my opinions. The role within Waverley Care allowed me the freedom to initiate events and to pursue ideas I had for new ways to attempt to meet people's needs. There was also a public ministry, notably conducting funerals but also leading remembrance events, including World AIDS Day gatherings and, on two occasions, leading the time for reflection in the Scottish Parliament.

I have shown that the ministry I exercised at Waverley Care was an active expression of both diaconal and priestly calling. I will now discuss the personal impact that the ministry had on me.

5.3.3 The personal experience of ministry within Waverley Care

The opportunity to minister within that particular setting and with a distinctive group of people was inevitably both an honour and a challenge. The challenge often came as I sought to be true to my Christian calling and discipleship whilst at the same time making myself accessible to the people I was amongst. One issue was that of language. Many service users had little formal education and assumed that the use of complex language by professionals was an indication that communication would be difficult. This was exacerbated by the spiritual nature of my task. I sought to express complex and deeply spiritual concepts in

ways that were understandable and acceptable. I was clear that one of my tasks was to speak truth, to witness to the Gospel in whatever way was possible while at the same time honouring the secular nature of the agency and the right of service users to avoid any kind of religious conversation.

The challenge was more intense when preparing funeral and memorial services. I wished to offer hope, to offer comfort and to avoid bland generalisations or a dependence on texts which had little real relevance. I needed to be true to my own beliefs and simultaneously to meet the needs of the service users, whilst not compromising my own integrity. As I grew into the role and gained experience, I found more comfortable ways to manage that dichotomy. I found language that was meaningful to both a secular and a religious audience, such as the prayer/poem I shared above (4.2). The ministry was at the very edges of society with some of the most marginalised people in the community. I was able to engage with those people in their pain, their despair and their loss. For me, that engagement was a clear expression of the experience the disciples had of being at the foot of the Cross, the very place where we as active Christians seek to find some understanding of pain and despair and the place where I find myself best able to express my longing for God.

5.4 Grounding the reflections in Scripture

One biblical passage that has helped me to reflect on my experiences and to explore them further in prayer is found in St Paul's second letter to the Corinthians. Chapter thirteen of that epistle, which has been described as his hymn to love, says in the final verse 'And now faith, hope and love abide, these three; and the greatest of these is love'.⁷³ Faith, hope and love have all featured in the journey of ministry amongst people living with HIV. I will examine the impact of each in turn.

5.4.1 An expression of faith

It was important to me to find ways to express my faith as I ministered, and I aimed to do that by showing something of God's love to the service users and to my colleagues. I tried to be guided by the words of St Teresa of Avila:

⁷³ 1 Corinthians 13:13

Christ has no body now on earth but yours
 No hands but yours, no feet but yours.
 Yours are the eyes through which Christ's compassion is to look out to the
 earth,
 Yours are the feet by which He is to go about doing good
 And yours are the hands by which He is to bless us now.⁷⁴

I was given a unique opportunity to minister in a particular place at a particular time. Circumstances came together in a distinctive way to create a genuine need among a group of people who were marginalised and the targets of regular discrimination. They are the very people amongst whom I believe Christ would have ministered, people labelled as sinners and outcasts.⁷⁵ They are people whom the faith communities struggle to engage. Some may have been the recipients of outreach in the form of soup kitchens or food parcels, but few have had the experience of being treated as equals, as God's children to be respected and honoured.

That is my core learning from this research. I have learned more about the nature of God from the people who gave their time in interview, the people who have shared their stories, than I have from many years of attending religious services. People have taught me what it is to communicate from a place of vulnerability; what it is to share at the deepest level and to retain mutual care and respect throughout that process. People have taught me how to allow myself to be ministered to, to let go of my own sense of self as minister and healer and source of knowledge; to be open to the expressions of love and care and compassion that come from people with limited access to the trappings of learning, but who are experts in their own lives. The range of experience within those lives has been extraordinary.

Paul Ballard in a 2009 article suggests that prophecy is one of the defining features of the exercise of chaplaincy. His words resonate:

[T]his is essentially the prophetic task. The prophet is required to read the signs of the times in the light of the fundamental revelation and to understand that revelation as it both illuminates and is illumined by the pressures and demands of the world. This is the gift the prophet brings:

⁷⁴ St. Teresa of Avila (1515-1582) Accessed 21:6:2016
<http://www.catholicity.com/prayer/prayer-of-saint-teresa-of-avila.html>

⁷⁵ See Mark Chapter 2.

to shed meaning and light on a situation so that those who act can make decisions that serve the Kingdom. The prophet is above all a positive presence, representing the possibility of hope and change, claiming that it does not always have to be as it is but that we can struggle for the future. To do this, however, the prophet lives among the people, sharing in their hopes and fears, and in the debates that are part of communal living. The prophet, therefore, will be one voice among many, endeavouring to catch the ear of those around, often ignored and sometimes persecuted. But the prophet is not there for his or her own sake but for the sake of the people and the world God loves (John 3:16) (Ballard, 2009:23).

In particular, Ballard's words '... a positive presence, representing the possibility of hope and change...' has strong resonance with my understanding of what the ministry within Waverley Care sought to achieve.

5.4.2 A time for hope

Anthony Kelly in his book *Eschatology and Hope* makes a useful distinction between hope and optimism. He notes that:

Optimism is no bad thing of itself. It is a kind of implicit confidence that things are going well in the present situation... In contrast, genuine hope is always "against hope". It begins when optimism reaches the end of its tether (Kelly, 2006:5).

In the early days of HIV there was little room for optimism and so hope became something of a lifeline. One of my aims was to find ways to help people to hold onto some hope, often in the midst of deep despair. Feedback would suggest that this was achieved at least some of the time. One service user, who says that he would not be alive without my intervention, tells me that what I offered him was hope.⁷⁶ He could not see any possibility of change in his life but he could see that I have a deep sense of hope that emerges from my relationship with Jesus Christ and that was enough to give him something to hang onto. Another man told me that he was unable to pray, that he could not see how it would make a difference, and yet he was comforted to know that I do.

A service user called Stuart died in 2013. He developed lung cancer and died within eighteen months of his diagnosis. He was someone who had engaged in vigorous debate with me about the existence of God, regularly telling me that it

⁷⁶ Personal conversation February 2016

was not credible that I could have belief in a deity. As he became more unwell, he became less strident in his views. By the time he died he was saying to me 'I'd like you to be right - but I don't think you are'. That shift represented a significant injection of hope into his life and, perhaps, made his passing from this life a little easier.

In his book, Kelly goes on to suggest:

Hope is at home in the world of the unpredictable where no human logic or expectation is in control. It resists any easy assurances of pretending to manage what in fact intrinsically resists management. It relies on something that comes from outside the system. In this respect, it is never far from humility, for it acknowledges that in birth and in death, in the wonder of life and in the intimations of art, human existence is never a realm of total control (Kelly, 2006:5).

This latter point about control is very important when considering the experiences shared within this thesis. The people amongst whom I ministered were very aware of how little control they had over much of their lives. They could not control what was happening within their blood stream or how their immune system was reacting. Once effective treatments became available they could take the tablets, but had no control over the side effects or whether the treatment would continue to be effective for them. They had no control over the stigma they encountered, no control over the reactions they received when they disclosed their HIV status. *Astrid* makes this point well at section 4.4 when she describes how she took control of her physical environment in an obsessive way. She now realises that this was an attempt to find something within her life that she could control and that she poured an enormous amount of energy into that enterprise.

Discussions with service users when I was preparing to leave allowed them to disentangle what they thought was distinctive about the spiritual care service. Several spoke about hope. *Sean* said that my own obvious faith and confidence was an expression of hope that people could relate to and engage with.⁷⁷ He drew a distinction between the approach of other staff who were there to do a job, however well they fulfil that role, and the approach of a spiritual care provider who was there to express a vocation. It became clear to me that

⁷⁷ Conversation April 2016

service users had been able to understand something of the nature of priesthood. They had understood that the performance of task and the commitment to living a values based life, following in the way of Christ are inextricably linked for those of us who are in authorised ministries. I am not able to switch off my priesthood. It is both who I am and what I do. Hope is an inherent element of that. Kelly's final chapter concludes:

[H]ope moves through time in an energy flowing from the heart of Christ, crucified and risen. Its forward movement is powered and sustained by the Spirit of Jesus (Rom 5:5). Yet its path is traced and earthed in the eucharist. The sacraments of the church anticipate a universe transformed and brought to its fulfilment (Kelly, 2006:202).

The reference to the eucharist, to the central Christian act of worship at which, as an ordained priest, I am privileged to preside, makes a clear connection between the expression of hope within a secular context and the engagement with sacrament. Through that comes the nurturing of self, which makes my expression of hope possible. I find that I am sustained and nourished by presiding at and receiving Holy Communion. The eucharist is for me the place where my ministry comes together, the place where there is no 'out there' and 'in church' but rather a deep connection between the elements of my ministry which combine within the body of Christ.

5.4.3 The experience of love

Very early in my ministry at Waverley Care I realised that many of the service users had little experience in their lives of love. Their experiences of being children had often been miserable. Many had been brought up in deprived areas of the city where excessive use of alcohol, domestic violence and what we now describe as abusive parenting were ordinary stories. They were in families where their parents were unable to cope, often because they were trapped in cycles of deprivation. Time and again, I heard how young boys had tried to protect their mother from an abusive partner. There were stories of childhood sexual abuse. I heard of time spent during childhood in the care system, some of those people had then gone on to incarceration in a Young Offenders Institution and some of those had found their way into the adult criminal justice service. The underlying theme was of insecurity and an uncertain lifestyle and future.

5.5 John Bowlby and attachment theory

Over the years, I have come to recognise that one of the ways in which I and other staff made a difference with our service users was to model a healthy attachment. John Bowlby researched extensively into the attachment between child and mother and the impact of both healthy and unhealthy attachments on the development of the individual. His findings show that children who are able to build a secure attachment, that is to learn that they will not be abandoned by their mother and that it is safe to venture away from her, grow into healthier and more secure adults. By contrast, those whose mothers have not been able to offer consistency and the reassurance that their children need, may behave in ways that suggest a deep seated insecurity and lack of trust in other people (Bowlby, 1969). This is an area of psychological health that surfaces in many of the service users we see. One area of my ministry as chaplain has been to actively seek to build healthy attachments, to challenge the assumptions that people cannot or will not change at this stage in their lives and to support people to become more fully themselves. This desire to give more chances, more leeway than might seem sensible, to go the extra mile, and to commit to supporting service users for the long-haul links with a Christian imperative to be 'a fool for Christ'.⁷⁸ This can be perceived at first sight as being soft with people or having a naive approach. I would argue, however, that it is a more challenging way to work with people and has the potential to reap considerable benefits. It is inevitably easier to manage a service within which there are clear boundaries and firm rules that are never ignored. Many services, particularly those working with people who have challenging behaviour, are clear that breaking the rules brings immediate consequences. This approach inevitably makes for a safer environment, physically and relationally, but it might not make for the optimum opportunities for development. To remain alongside people when their behaviour becomes challenging, to support people time and again as they relapse in their behaviours requires a mature professional practice and a degree of self-confidence. It requires appropriate risk assessment and good supervision in order to ensure that there are still good boundaries, even though those boundaries may simply be in a new place.

⁷⁸ See 1 Corinthians. 4:10

5.5.1 Case study on attachment

When I met *Sadie* sixteen years ago, she had no idea how to engage with someone who was not looking for something from her. She only understood relationships that were based on a transaction, whether that was drugs, money, sex, information or something else. For the first two or three years that I knew her, *Sadie* consistently tested me. She would lose her temper, hurl abuse, make complaints, storm out of meetings; she would also apologise profusely, buy gifts (which I usually refused), and seek ways to check out whether I would see her again. I attempted to offer her consistency in my responses. I did not respond to her anger, nor did I respond to her attention-seeking behaviour. This was in contrast to her experiences over many years of working with professionals when her behaviour would deteriorate and sanctions would be imposed. For instance, Milestone staff had struggled with her over the years and she had been asked to leave early on a number of occasions. Her response to the sanctions was to anticipate that they would be repeated and so she behaved in ways that ensured such an outcome, allowing her to save face (in her opinion) and to say 'I knew that would happen'. *Sadie's* reputation suggested that no-one could get close enough to work therapeutically with her. Gradually she began to trust that I would be there and that I would continue to offer care and support to her. I would call her to account when her temper got the better of her, I would try to help her to see her own part in the decisions that were made about her, but I would not reject her.

Sadie became strongly attached to me. For a time she was quite dependent, seeking advice for almost every decision she made. We spoke daily for a period of about two years. Gradually, she began to take a little more responsibility for herself. It felt as though she was finally becoming an adult and trusting in her own decision-making processes. One day I overheard *Sadie* telling someone else that she loved me. She was not able to express that directly, but the fact that she was able to identify and name her engagement was a turning point. I began to notice that she was engaging better with other staff and, more importantly, with her peers. She started to describe people as friends, and she began to learn about mutual support and care. I am no longer *Sadie's* main source of support. She is now linked in with the Waverley Care Community Outreach service and has a healthy and appropriate relationship with her worker.

Sadie is rarely able to express her emotions and tries very hard never to cry. On the day that I left Waverley Care, she gave me a gift with a card which simply said 'I feel sad'. The expression of that simple phrase, albeit in a note rather than verbally, is an indication of the change that happened for her. She was finding a way to connect with her own emotional response and to recognise that response for what it was. She did not need to express her emotions with inappropriate anger or by avoiding the situation completely, both of which were regular coping strategies for her. Her expression of sadness allowed for a more honest and open conversation between us and a better ending of our relationship.

Liz Marr, the senior manager at Waverley Care Milestone discussed the concept of healthy attachment with me:

There is a period where people will attach completely and will be dependent on you, but it's a time when they need it and it's never in a place where you can't then move people on. Because you know your boundaries, I know my boundaries; I know what my limits are. I know when people do need to be moved on. And they sometimes need quite a lot of help to do that. But it doesn't mean it's the wrong thing to do. I think one thing is the lack of any consistency or anyone who's stayed in the lives of most of the people. The one common denominator is lack of a consistent family member in all of our service users and I think we in some way provide that. It's a different relationship but it is consistent and it is a lengthy kind of relationship. For me that's one of the things that Waverley Care does well, we build those relationships and we get that it's the relationships that you have to have in order to work with people and build back trust. If we weren't being like that then I don't think we'd be the organisation that we are (Marr, 2016).

The majority of people who regularly use the Milestone residential unit have complex problems and poor coping strategies; supporting those complex needs is one of the areas of Waverley Care's work that is funded by the local authority. Identifying some of the reasons for the complex behaviours begins with observation. Many of the service users have little or no contact with their family. Some are unclear about the identity of one or both of their parents, many have spent time in the care of a local authority and some have been rejected because of their lifestyle choices or their HIV diagnosis. It is not uncommon for a service user to seek support to find their children. Men have often lost touch with the mother of their children and, as they age and their children reach young adulthood, they have a desire to make contact. Amongst

the women, some were persuaded to give children for adoption in the early days of HIV, some have had their children taken into care, usually as a result of poor parenting linked with drug use and some have voluntarily asked for local authority care as they knew they could not cope.

My observations are supported by Marr as she describes the culture she found in her early weeks in the unit:

We were looking at people who had very poor social skills, very poor social backgrounds, little if any role modelling and so behaviours were, you know. People were swearing all the time, they didn't really know how to say please and thank you. If they were angry you knew about it. Whereas the places I'd worked before there was always the sense of what was right and what was wrong. And some social skills. It really resonated for me that people hadn't had the time invested, they hadn't had people around them that would sit with them and listen beyond that. If I had met a lot of the people that I was looking after in the street or if I was in the pub and somebody was behaving that way, I would have gone the other way. I would have sat on the other side of the pub not to get involved in that. But my job was to get past that and see the real fear or anxiety or need to be loved or accepted in people. And we got the opportunity to do that. I think that's why it became obvious to me that that's what I wanted to do and it was the right place to be.

The situations I have described above each have their own problems and longer term consequences. For instance, one woman I worked with, *Chrissie*, was in a violent relationship when her son was a young child. She coped by drinking and turning to drugs. Realising that she was putting her son at risk by her lifestyle choices, she asked for him to go into local authority care. He was looked after for nine months. He is now in his mid 30s and he continues to blame his mother for his own problems (he gambles and has trouble sustaining work). She, in turn, cannot get beyond the guilt she feels at her inability to parent well at that time in her life. Their relationship is poor; she compensates by spending money on him, he responds by bullying her. Neither can see that the decision she made was responsible and grounded in her love for him, although she was unable to display or express her love at that time. The pastoral task was to support *Chrissie* to feel forgiven in order that she can move on. There is an element in this of repentance. She needs to take some responsibility for the lifestyle decisions she made. Timothy Radcliffe describes this process:

We begin by repenting of our sins, then, not so to wallow in guilt but to remember that our little personal stories are part of that larger narrative,

in which we come from God and go to God, and to take up the journey again (Radcliffe, 2008:21).

That pastoral task discussed above, based as it is in self-reflection for *Chrissie*, is not one that is easy to initiate. In order to reach a stage where she was able to reflect on her own responsibilities and to seek forgiveness which then enabled her to move on, she had to establish a deep trust relationship with me. She had to trust that she was not being judged, that she would not be rejected if she admitted some personal responsibility and that she would be supported as she sought ways to move on, to take up the journey again. The trust came out of an attachment, which in itself was the result of several years of consistent engagement.

5.6 Using bereavement research to provide a theoretical framework

I have looked at work on death, dying and bereavement as a way into finding a model for thinking about the impact of HIV on those people who are living with the virus. I find that there are many useful parallels which help us to grasp the depth of the experience. I will consider the work of two researchers.

5.6.1 Elisabeth Kübler-Ross' stages of dying

Perhaps the best known author on death and dying is Elisabeth Kübler-Ross, whose 1969 work, *On Death and Dying* has been credited with changing attitudes to death. In the 40th anniversary edition of her book, the foreword states, 'The book you are about to read, or reread, is one of the most important humanitarian works on the care of the dying written in the Western world' (Kübler-Ross, 2008). Kübler-Ross was a psychiatrist who became interested in and then involved with end of life work. In the early 1980s she took a keen interest in the care of people who were living with and dying from HIV. She had plans to open an AIDS hospice in Virginia in 1985, but failed to raise the necessary money or to gain planning and building permission. Her book, *AIDS: the ultimate challenge* was published in 1987. In that book she restates her (1969) 'stages' of dying which she describes in a linear way. She explores a journey through the stages of denial, anger, bargaining, depression and

acceptance (Kübler-Ross, 1987: 5-11). Most of these stages can be related to the lived experiences of people who have an HIV diagnosis, although I think that they are not an ideal descriptor for all situations. I will consider each of the stages in turn.

5.6.1.1 Denial

The first of the stages is denial and isolation. Kübler-Ross writing in *On Death and Dying*, describes the reaction of the majority of the dying people she interviewed to their awareness of terminal illness, whether that diagnosis came at the beginning of their illness or towards the end of their lives. She says that the immediate response for most people was 'No, not me, it cannot be true' (Kübler-Ross, 1969b:loc 680). She then explains that denial serves a purpose for people:

Denial functions as a buffer after unexpected shocking news, allows the patient to collect himself and, with time, mobilise other, less radical defences (Kübler-Ross, 1969:loc 700).

Kübler-Ross is showing us that people have a very powerful and immediate emotional response and then find a way to manage their emotions in order that they can continue to function. She was dealing with news about a medical condition with a poor prognosis; for people living with HIV there are more nuances to consider. The people amongst whom I ministered may be in denial about their diagnosis and may use denial as a coping strategy. As suggested by Kübler-Ross, they may feel that they need to put aside the facts of their diagnosis in order to pursue life, but any healthy lifestyle, both for the individual and any intimate partner, must take the HIV into consideration. The impact of HIV is rarely only on the individual who is living with the virus. The person who has been diagnosed may have loved ones who are also in denial about their situation, not necessarily the HIV (which they may not have disclosed) but potentially their sexual orientation or their lifestyle choices. An HIV diagnosis can be the catalyst for 'coming out' to family or for disclosure of drug dependency which had been hidden.

People who find themselves trapped in the stage of denial manage and live with that denial in a variety of ways. Some deliberately ignore the situation and any health advice they have been given, and live in a hedonistic way. Others bury

themselves in work or hobbies and are able to deny the diagnosis until they begin to show symptoms of illness. As a carer, whether or not that is in a professional capacity, it is not always possible to deal directly with denial as such an encounter can easily become confrontational. Stating and restating facts, however clearly, is not a good basis for therapeutic intervention. In the case of an HIV diagnosis, where the denial can sometimes be linked to avoidance of behaviour change or engagement with health professionals, time will eventually move on and the person's health will deteriorate at which point the denial will probably cease. Inevitably, there is pressure from public health colleagues to work through any denial in order to minimise the possibility of risk taking behaviour and the resultant onward transmission that could occur.

The oral histories which form chapter three of this thesis show how most people did come to terms with their situation. *Astrid* is an example of someone for whom denial was a feature for some time. She described how she stayed away from the ante-natal clinic for the duration of her pregnancy and only began to engage with HIV services when she had to take her child for regular testing to discover whether or not he had contracted the virus from her.

5.6.1.2 Anger

Kübler-Ross states that the logical next statement after 'It's not true' is 'Why me?', and she describes how this often manifests in dissatisfaction with the care and support that is being given (Kübler-Ross, 1969: loc 867). This is something that manifests within HIV services as well. Dr. Brettle and Dr. Jones described incidents within their clinics and on the in-patient ward of the Infectious Diseases Unit. Some of that behaviour was related to drug misuse, but some was simply the result of anger that the person was unable to control. In the days when Milestone was still functioning as a hospice, there were regular incidents arising from angry responses either to staff or to other residents. Kübler-Ross makes a plea within her book for 'tolerance of the patient's rational or irrational anger' (Kübler-Ross, 1969: loc 907). In my experience, tolerance proved easier to offer on some days than others and it was easy for particular service users to be labelled as angry people rather than as people who were struggling to manage an angry response to their situation.

We continue to see a great deal of anger on the part of service users. Anger may be directed at those who may have infected someone, at those who

discriminate against people living with HIV, but most often anger is directed at service users themselves for having contracted the virus. This latter has been especially true in recent years when people have had good public health information but have still chosen to take risks with their sexual health. For instance, Colin was married to a woman when I met him. He was a member of a conservative church that told him that it was wrong to be a practising homosexual. He therefore tried to sustain a heterosexual relationship. Colin was often unhappy and found it difficult to cope with the internal tension of knowing he was one person but pretending to be someone else. He occasionally sought comfort from other men by visiting Public Sex Environments (cruising grounds) for anonymous sex. On one of these visits he contracted HIV. Colin turned his anger on himself and spent many hours berating himself for being 'an idiot'.

5.6.1.3 Bargaining

This stage is seen by Kübler-Ross as one that can be helpful in the short term to the patient. For the dying person it is usually a form of postponement. For instance, she gives an example of a very sick woman who was desperate to attend her son's wedding but whose dependence on medication appeared to make that impossible. She worked with the medical staff and made promises to them, to herself and to God with the result that she was able to make the wedding (Kübler-Ross, 1969: loc 1398). Kübler-Ross devotes only a few lines to bargaining in her 1987 book on HIV. In clarifying what she means by this stage, she describes a situation where a female prostitute whose child was also HIV positive told her 'If my child gets well, I promise I will live like a nun thereafter' (Kübler-Ross, 1987:8). In fact, mother and child died within seven months of each other. This is perhaps an example of the desperation that often accompanies this time in someone's life. Overall, the idea of bargaining fits less well with the experiences I have witnessed than Kübler-Ross's other stages.

5.6.1.4 Depression

Kübler-Ross's fourth stage is depression and this is a reality for far too many people who are living with HIV. An article in the *American Journal of Health-System Pharmacy* suggests that the 'lifetime prevalence of depression in patients infected with HIV has been estimated at 22-45%' (Penza, Reddy and Grimsley, 2000:376). In her paper published in *Psychosomatic Medicine*, Jane

Leserman links the experience of depression with faster disease progression (Leserman, 2008:539). I am not convinced that the depression experienced by people living with HIV is a stage through which they can move. Rather, it seems to be a condition with which they live. Many of the service users I see take medication for their depression, while others employ a variety of coping strategies in order to mitigate the effects. My observation is that it is a present reality for many people much of the time.

5.6.1.5 Acceptance

The fifth of the stages in this model is acceptance. Here, acceptance refers to an ability to live with the situation as it is, for the individual to be neither depressed nor angry. Kübler-Ross' original work was about people who are near death and she suggests that the person who has reached a stage of acceptance is likely to be tired and weak. She notes that this is not a happy stage, rather one that is void of feelings (Kübler-Ross, 1969: loc 1961). In her book on AIDS, she has a more positive definition which is evidenced in the creation of community amongst people who are living with HIV. She gives an example of peer support amongst gay men as an example of the way that a move towards acceptance makes a difference for a wider group of people (Kübler-Ross, 1987:11).

In my understanding, acceptance implies that any internal conflict has been resolved and the individual concerned is able to integrate their status as someone who is living with HIV into their experience of being in the world. My interviews show that some people have found a way to live positively with their HIV. *Astrid* is, perhaps, the best example of this. She is open in many situations about her HIV status, has worked as a peer supporter and educator and regularly challenges examples of HIV related discrimination. She has told me that each time she discloses her status it becomes easier; each time she experiences acceptance from others she is a little more able to accept herself. It may be that as she models acceptance of self and others, she encourages those other people to move towards self-acceptance.

Other respondents, however, continue to live with the internal tensions. *Sean* has never disclosed his HIV status to his wider family and speaks in interview about his fear that people might guess his health condition. He is always conscious of 'need to know' as a basis for disclosure of his HIV status. For

example, when I visited his father in a nursing home at the end of his life, I was introduced as a family friend rather than chaplain to *Sean* and his family.

5.6.1.6 Summing up

Kübler-Ross offers a model that has much to offer at some stages, but is less helpful at others. I have shown above how denial and anger are important stages for people who have been diagnosed with HIV. There is less evidence given by Kübler-Ross, or observed in my practice, that bargaining is in any way significant for this group of people. Depression is a significant feature in the lives of my service users and her emphasis on that is helpful. Her final stage, acceptance seems, to me, to be an important concept for the service user group, but I am not sure that Kübler-Ross approaches it in a way that is entirely helpful. It seems that acceptance is something of a two-way process, the more one experiences acceptance the better able one is to accept the reality of the situation.

I find that there are aspects of Kübler-Ross's work that resonate but I am not convinced by the linear nature of her model. My observation is that people might simultaneously be experiencing denial and anger and depression, each one feeding off the other. For many of my service users, there is no sense of moving through a process. The trap that people can experience of cycling between denial and anger and depression is one that often leads to unhealthy coping strategies. People may use or revert to using drugs, alcohol or sex as a means of escape. There are clearly potential dangers, both physical and psychological, associated with these behaviours.

5.6.2 William Worden's tasks of grieving

I have found William Worden's model as described in *Grief Counselling and Grief Therapy* to be more congruent with my experience (Worden, 1991). Although his work focusses on bereavement and the impact of death, there are a number of parallels with the experiences that I have explored and the issues that they raise. If we substitute the word loss for death, it becomes clearer. A diagnosis of HIV brings with it a sense of loss; loss of the future one had anticipated, loss of the healthy physical self, loss of control over the impact of the virus on the immune system. In their interviews, people described the loss of friendships, of relationships, of the ability to work or to be physically active.

Worden defines four tasks: to accept, experience, adjust and re-invest, which provide a framework that I have found helpful for looking at the impact of an HIV diagnosis. The differences between Kübler-Ross and Worden are in their understanding of how people process their emotional responses. Kübler-Ross is clear that the stages of grief that she describes may overlap, and that some people may bypass a stage entirely, but her model envisages movement through these stages and along a continuum. It is not unusual to hear professionals say that someone is stuck at one stage or another and to express concern that they need to be supported to move on from that stage to the next in order to reach the goal of acceptance. Worden, on the other hand, suggests that a bereaved person will engage with one or more of his tasks of grieving in so far as they are able at any given time. They may then withdraw from their own active therapeutic process for some time, returning to the tasks when they are emotionally and spiritually ready to do so. In my field, I am defining the four tasks in this way: to accept the diagnosis, to experience the reality, to adjust to that new reality and to reinvest emotional and spiritual energy. My observation is that people who have been diagnosed with HIV manage their diagnosis and life with HIV better if they are able to engage with these tasks. I will consider the four tasks in turn.

5.6.2.1 Accepting the diagnosis

Worden's work is, of course, on death and the language he uses assumes a bereavement. I am applying his thinking to the concept of loss, assuming that an HIV diagnosis brings with it some significant losses. We have seen that people experience loss of health, loss of the ability to be open with others about one's health and personal situation, loss of freedom in sexual relationships, loss of freedom from daily medication. There may be additional losses, such as partner, or relationship with parents, or friends. Worden describes the task of accepting the reality of the loss: 'Part of the acceptance of reality is to come to the belief that reunion is impossible, at least in this life' (Worden, 1991:11). In other words, wishing for things to be different will never change the situation. Things are how they are and the task of acceptance is to fully believe that to be the case.

Worden recognises that some people will be unable to accept their reality. This he describes as denial, which he says 'involves either the facts of the loss, the

meaning of the loss, or the irreversibility of the loss' (Worden, 1991:11). For someone who received an HIV diagnosis in the days before effective treatments, the display of some or all of these responses would not be surprising. Many people have told me that they asked for more than one test at the point of diagnosis. They simply did not want to believe what they were being told, especially if they had no idea they had been at risk. An example of this is those women who were infected through a sexual relationship when they had no idea that their partners had engaged in high risk behaviour, such as injecting drugs, having sex with prostitutes or having sex with men.

Some of my interviewees were not at all surprised by their diagnosis, having perhaps, engaged with a task of acceptance before the formal diagnosis was received. Michael, for example, knew that his partner was HIV positive and was severely immunocompromised. It seemed likely to him that he had been infected but he was in no hurry to go for the necessary blood test. At that time there was no treatment and he felt that he had little time or emotional energy to focus on his own health as his partner was extremely unwell. *Peter* knew a number of men who had been diagnosed, knew that he had taken similar risks, and so was not at all surprised when he discovered that he was HIV positive.

For *Astrid* however, it was a shock, which was compounded by the advice to seek a termination of her pregnancy. Her response was to stay away from the medical profession until she was in labour. Her behaviour fits Worden's description of denial: she was not ready to think about the facts, the meaning or the irreversibility of her situation.

5.6.2.2 Experience the reality of the diagnosis

Worden describes this as 'work[ing] through the pain of grief' (Worden, 1991:13). This is a period of time that Worden sees in a physical way. He uses a German word for pain, *Schmerz*, which he chooses because 'its broader definition includes the literal physical pain that many people experience and the emotional and behavioural pain associated with loss' (Worden, 1991:13). People may experience physical pain when they receive their diagnosis; *Astrid* spoke to me about feeling nauseous whenever she thought about the situation she was in. From my research, I think it is more likely that people will experience emotional, and spiritual pain. Responses to that pain differ, of course, from person to person. Michael chose to self-medicate with alcohol and drugs. *Peter*

found a religious community that was able to minister to him and help him to move on.

For all of my interviewees, their diagnosis was of a terminal illness. None of them expected to survive for more than a few years. Annie, who was diagnosed in October 1985 told me that she expected to be dead by Christmas. For her, the task of experiencing the reality of her diagnosis came much later, as she began to trust that she would live, that she had a future with this virus. This task of experiencing the reality, working through the pain, is probably the one that people revisit most frequently. Each instance of rejection or discrimination touches this area of a person's experience. Each decision about disclosure links with the painful reality that HIV is a different kind of virus.

5.6.2.3 Adjust to an environment in which the deceased is missing

Worden defines his third task as 'adjust[ing] to an environment in which the deceased is missing' (Worden, 1991:15). As I suggested above when I discussed the task of acceptance (4.5.1.1), the adjustment that is needed is to an environment in which full health is missing, an environment within which life plans have had to change, an environment in which life without HIV will never return. Worden recognises this experience when he says, 'It is not unusual for the bereaved to feel that they have lost direction in life' (Worden, 1991:16).

Once the individuals had adjusted, at least in part to their diagnosis, they began to experience the reality and the societal stigma that was never far away. For people with an HIV diagnosis, especially in the days before effective treatments, these tasks of experiencing the reality and adjusting to a new paradigm cannot be separated. Not only were they dealing with a changed future, they were living with a stigmatising disease that impacted on every part of their lives. The immediate questions would be who to tell, how to tell, and when to tell. Should one disclose to family, to close friends, to potential sexual partners? People were reluctant to tell their GP for fear that they would experience discrimination if the information was on their medical records. There were travel restrictions in place, for example the USA implemented restrictions in 1987 and did not lift that restriction until 2010 (Global database, date unknown).

5.6.2.4 Emotionally relocate the deceased and move on with life

Worden's definition of the fourth task in the revised (1991) version of his book is 'to emotionally relocate the deceased and move on with life' (Worden, 1991:16). In the earlier version this was described as 'withdrawing emotional energy from the deceased and reinvesting it in another relationship' (Worden, 1991:16). The earlier language, which Worden defends in concept was changed because he felt it was easily misunderstood. For our purposes, that earlier definition is perhaps an easier phrase when applying the model to something other than bereavement. In either case, moving on with life is the goal and became achievable when viable treatments were made widely available. As people became stable on HIV treatment and found that their energy levels improved, they began to look forward, to believe that there were years rather than months in front of them. In his interview, Michael described how he began to take care of himself, to avoid dangerous sexual encounters, to reduce his use of alcohol and recreational drugs and to find healthier ways to spend his time. *Astrid* told how she had met a man who was willing to become involved with her and her son. The subsequent marriage was not sustainable, but the momentum to look forward and take responsibility for her future had begun. Annie had never been in a serious relationship. At the time of her diagnosis, she was living with and caring for her parents. Once she became stable on treatment and began to socialise with people who were also living with HIV (through Waverley Care), she embarked on two relationships. Sadly, both of those men have died and she is again living alone.

Worden describes the task for a counsellor (or other support worker) who is seeking to help:

The counsellor's task then becomes not to help the bereaved give up their relationship with the deceased, but to help them find an appropriate place for the dead in their emotional lives - a place that will enable them to go on living effectively in the world (Worden, 1991:17).

From our perspective, we can translate that task into supporting the person to find a way to live with the emotional, psychological and spiritual reality of their HIV which enables them to live effectively. Worden discusses the danger of not dealing with this task as '*not loving*' [his italics]. He says that 'The fourth task is hindered by holding on to the past attachment rather than going on and

forming new ones' (Worden, 1991:17). This is perhaps illustrated in *Sean's* story where he discusses his inability to re-engage in a sexual relationship with his partner after his diagnosis, his decision to remain celibate, and his subsequent emotional engagement with new friends whom he has met as a result of this diagnosis.

I have discussed two models borrowed from the world of grief counselling. I have shown that Kübler-Ross has something to offer in helping us to understand the impact of denial, anger and depression although the linear nature of her process is less helpful. My experience suggests that people do not deal with these aspects of their diagnosis in a straightforward way, rather that situations arise that make people realise they have unresolved issues to manage. Worden's tasks of grieving offer a model that I find more useful. The model allows us to recognise that people engage to a greater or lesser extent with their own processes at different times in their lives. Worden allows for the possibility that people will revisit these emotional tasks, perhaps on many occasions, and that the process of dealing with the loss is one that never ends.

5.7 Using Worden to understand my personal experience

In March 2016, towards the end of this project, I heard that my post at Waverley Care was to be made redundant. A decision had been made that it was no longer possible to fund a distinctive spiritual care service and the agency would look at how it might meet those needs in a different way. I decided not to accept the offer of redeployment and was accepted for voluntary redundancy. As I observed myself responding to my situation, I was surprised at how closely my process mirrored that which I had observed in people who had received the diagnosis of a blood borne virus. During the sixteen years of my ministry within Waverley Care, I did all that I could to get alongside people and to empathise with their situations. I was seeking congruence, described by Carl Rogers as one of the pre-requisites for a healthy therapeutic relationship (Rogers, 1992:827). I had done all that I could to empathise with my service users, but I now found myself in a situation where I could more nearly walk in their shoes. I will explore the situation in which I found myself in relation to each of the 'tasks' described by Worden and considered more fully above.

5.7.1 Accept the reality of the situation

The communication regarding redundancy was completely unexpected. I was in shock, as were many of my colleagues. I spent several days speaking to people and saying (and hearing them say) 'I can't believe it'. I found myself repeating the story over and over again. I found myself rehearsing what had been said and how I might respond. None of this felt real. I was functioning as though I were in a parallel universe - I had no idea who to believe, who to trust or how it would be appropriate to respond. I cried for many hours. I found myself unable to sleep. I became self-obsessed and found it difficult to concern myself with anything other than my immediate situation. My world had narrowed to one focus that made me miserable. I found it hard to imagine what the future might hold. I began to think about the losses that were involved, loss of relationships with my service users, loss of identity, loss of purpose, loss of income. I began to understand a little more what the experience of acceptance had involved for my service users. I tried to convince myself that my situation was sad but not terminal, that I would find a new focus for my ministry. I knew that I would eventually find a way to move on. I began to reflect again on the parallels; for me this was a life-changing moment, things would never be the same again, but there was a need to accept the reality of that. For my service users, their diagnosis of a life limiting health condition was clearly one from which things would never be the same again. I do not wish to suggest that the two experiences are in any way directly comparable: clearly, my situation is on some level temporary, and yet the emotional response and the experience of grieving were remarkably similar.

5.7.2 Experience the reality

As I began to process the situation, I began tell people what was happening. After a few days, I told a small number of service users that I would be leaving and found myself back in the emotionally traumatised place from which I had tried to move. Each time I told someone else, I found that there was a little more work to do on acceptance, a little more engagement needed with my own process. Accepting the reality and experiencing that reality became something of a see-saw experience. I found ways to feel better and to focus on the opportunities that might now be open to me. I had to share my news with people who felt that they were being penalised and I found myself back in the

place of despair. An example of the responses I encountered comes from Annie who said, 'We had to fight to get Milestone, we had to fight to get combination therapy and now they're taking Marion away from us'.⁷⁹ I have no doubt that in her emotional response, she felt that not only was I being disregarded but so were the service users who did not want to see this dedicated service ending.

This response confirmed for me that Worden's theory has substance. I found myself engaging with more than one task, found that I could be having a better day and then something happened and I was in the most raw place yet again. The Kübler-Ross stage theory which would suggest that I might have been in denial and then found that I was angry before moving on to a place of despair, did not begin to describe my lived experience. There was no linear process, no tidy moving from one emotion to the next; no sense that I had dealt with a particular stage and was ready to engage with something else. The process was far more messy, far more chaotic, which in turn made it more difficult for those who were seeking to support me.

5.7.3 Adjust to the reality

The process of adjustment began for me in very practical ways. I began to look at the paperwork and other paraphernalia in my office and to work out what I needed to store (very little) and what should be destroyed. There were some tasks that I needed to complete before I left. For example, I had five urns of ashes stored in my office. One of those was from 2002. The person who had died was estranged from his partner who had full care of their young daughter. He was extremely proud of his daughter and spoke about her all of the time. His ex-partner agreed that the ashes should be retained until she was ready to do something with them. The years went on and I contacted them several times. The daughter was never quite ready to make a decision. It seemed that while the ashes were in my care she was able to avoid dealing with her emotional response, which was complicated. I met with her on two or three occasions and each time she wanted to hear something positive about her father, wanted to know that someone had good memories of him, in direct contrast to all that she had heard and remembered about him. He was one of the people who had been instrumental in the campaign group that worked towards the building of

⁷⁹ Personal conversation March 2016

Milestone and so she was able to reassure herself that he was safe and secure in a place that had great importance to him; and yet she was unable to make the decision to scatter his ashes there. I suspect that the ashes represented for her and her mother the anger and hurt that were associated with this man's involvement in their lives. Letting go of the ashes would in some way represent a letting go of the hurt that he had caused. He had been very difficult when he was well, and as he became unwell he developed HIV-related dementia and his behaviour was extremely erratic. His daughter did not see him in the last few months of his life, and none of the staff who were caring for him would have recommended that she should visit, as he could be quite frightening when he was agitated. I made contact with that family again and explained that this time there was little choice, a decision would have to be made about dealing with the ashes. I met with the daughter before I left Waverley Care and she took the ashes away; she was still unable to fully let them go.

The other urns were less problematic. One was a man who had no surviving relatives whom I could contact and so I scattered his ashes in the grounds at Milestone, accompanied by staff who had known him. The others were collected by their relatives.

5.7.4 Emotionally relocate the deceased and move on with life (previously described by Worden as re-investing the emotional energy)

As I took my situation into my prayer, I began to see that God was using the circumstances I found myself in to offer new opportunities. I began to consider other forms of ministry, to be open to what God might be suggesting and to consider taking the risk of offering myself for something very different. There was a temptation to rush into something; I was not short of suggestions from well-meaning friends and colleagues. However, I realised that the task of re-investment is indeed a task and a process. I needed to engage with this task in the same way that I had found myself engaging without choice in the other tasks. I began to understand why Worden suggests that some people will never fully engage with this task (Worden, 1991:18). In some ways it would be far easier to avoid, to simply take a pragmatic approach and move on to whatever first presented itself to me. I began to realise that in order to honour what had been, to honour the people whose lives had touched mine, I needed to take the time to disengage emotionally in order to be in a position to engage afresh in a

new situation. Worden's description is helpful. I had a sense of 'parking' my emotional and spiritual investment in my Waverley Care service users, not abandoning them or simply moving on with barely a backward glance, but deliberately leaving them in God's hands. Once I had managed to do that, I would be free to engage with whichever of God's people I found coming my way.

5.8 Highlighting the ethical issues

During my last days at Waverley Care I had several conversations about what people would miss when the spiritual care service ended. *Sean* spoke about the role as 'glue' within the organisation, holding together the disparate parts and offering a cohesive vision. He described something that seemed to be like a thread of spiritual care weaving its way throughout the agency. On one level that is expressed as an explicit pastoral care for everyone, service users, staff and volunteers, within the organisation; at the same time there is an element of the role which was expressed as something like the conscience of the agency, the voice that expressed ethical concerns and considerations. That would extend from initiating discussions about where food was sourced for the residential unit to facilitating discussion within the agency on matters of ethical concern.

Ethical discussions, both within Waverley Care and within the wider Blood Borne Virus and Sexual Health sector, were something I initiated. We looked at issues such as suicide, responsibility for non-transmission, partner reduction and partner notification. In each situation, the focus was not on a pragmatic message or decision but on the ethical dilemmas for front line staff. For instance, we looked at the differences in the dilemmas for clinical staff rather than support staff when a patient made a decision to stop taking their medication. The discussions were nuanced and complex. The questions raised included: Was the individual capable of understanding the decision they had made and, if so, did they fully understand the likely scenarios at the end of their life? Had a variety of people from different disciplines spent time with that person and had they been offered a range of options? Was there a different treatment regime that might suit them better? This was balanced with a

question about whether clinicians fully understood the reality of some people's day to day lives and their inability to see any possibility of change.

The ethical role within the wider Blood Borne Virus sector was appreciated and the seminars were usually attended by more than fifty people. They were another opportunity to remind people that faith communities have a wide range of interests, that they are not simply focussed on their religious priorities and that they may even be relevant to contemporary life.

5.9 Summing up

In this chapter I have reflected on the research and have shared the impact on my personal spiritual journey. I have used the Stations of the Cross as a lens through which to reflect. I have framed my broader observations within models deriving from bereavement work. The final section will draw conclusions and offer some recommendations arising from my findings.

Conclusion:

This thesis has given voice to people whose lives have been changed by HIV. People who are living with the virus, and clinicians and other professionals who cared for them have shared their personal histories and experiences. The material contained within this thesis is unique; sharing it has been possible because of the depth of the relationships between chaplain, service users and colleagues within Waverley Care and the wider HIV sector in Edinburgh. My discipline is practical theology and I have shown how contextualising theology allows for extensive reflection on the issues.

The thesis evidences the impact that decisions about drug policy had on the spread of HIV in Edinburgh in the early 1980s. It discusses the particular nature of the epidemic in the city and recognises that resource-related decisions were made in direct response to the infected demographic. It documents the introduction of harm reduction measures for injecting drug users, exploring the thinking behind the decisions and the direct impact of HIV on public health policy in this area. Memories are shared by patients and clinicians of the impact of an HIV diagnosis in the time before treatment was available. The situation for men who have sex with men both before and after the introduction of treatment has been explored. Areas of concern, in particular the risk-taking behaviour of some younger men and the potential impact of chemsex on infection rates, are noted.

My thesis describes the creation of Waverley Care, the opening of Milestone House, a dedicated AIDS hospice, and the ethos that was developed within that organisation which created a centre of excellence. I suggest that there was a noticeable Christian influence on and within Waverley Care (discussed in some detail at 4.6.2), which contributed to the shaping of the agency. This includes the reservation of a seat on the Board of Trustees for the Bishop of Edinburgh. I comment on the impact of Waverley Care on the lives of people living with HIV and on its staff. In particular, I draw comparisons between the community that gathered at Milestone and became something more than the sum of its parts, and the gathering of community within faith settings which overtly seek to form community. A distinguishing feature of Waverley Care was that it continued to

employ a chaplain after its dedicated hospice provision was no longer being funded. I have shown that the chaplaincy service was valued within the agency and by service users, and that it contributed to the distinctive ethos of Waverley Care. I have voiced the anxiety expressed by service users that there will no longer be a dedicated spiritual care post.

It is not clear how Waverley Care will offer spiritual care in the future. In June 2016 the Waverley Care web site said:

We recognise that supporting you with your spiritual health is as important as looking after your physical, mental or emotional health [...] We offer non-judgemental spiritual support whether you have a religious belief system or not [...] For more information about this service contact your local office or our Head Office in Edinburgh (Waverley Care, 2016).

I am encouraged to read that the agency continues to value spiritual care, although it is not apparent how this service might realistically be accessed. My fear is that a lack of direct referrals to local offices or the Head Office will be used as evidence that the service is not required. I have shown that chaplaincy is a ministry of presence; its value can be recognised only when it is absent. This is evidenced at 2.7.2 when I quote Milestone staff contributing to an early review of chaplaincy, 'We'd only notice what you really do if you weren't here to do it. Perhaps that's what's so good - chaplaincy doesn't intrude, it's very powerful - this quiet presence'. I am not clear how people would identify spiritual need for themselves unless they require access to the 'services' of the church such as conducting marriages or funerals. I have never known someone attempt to articulate their own spiritual need; the task of the pastor is to tease out that need, often without ever naming it. Within Waverley Care, this has been exercised as a sacramental ministry (see 1.9); only time will tell whether there will be room for that to continue.

The chaplain's post within Waverley Care was part-funded by the Scottish Episcopal Church. That funding, sufficient to employ a chaplain one day a week, has now been transferred to Emmaus House, an urban retreat centre which hosts a weekly drop-in for people who are living with HIV and/or Hepatitis C. In addition, the Church of Scotland HIV Programme makes a funding contribution to support the work of Positive Help and funds a monthly Waverley Care African

Health group.⁸⁰ The overall reduction in involvement from the churches is a noticeable finding from this research; I question the message this gives to people living with HIV. Are they left wondering whether the churches have stopped caring?

The Scottish churches and their members were significant in the earliest responses to HIV. I have discussed their important contribution to service provision. I have critiqued the attitudes of some church leaders, which have been identified as hampering attempts to share harm reduction messages within schools and more widely. I have suggested that HIV has made a significant difference to attitudes within the churches towards human sexuality and has impacted on the discussions about same sex marriage.

My analysis of the impact of HIV on people who are infected or affected has shown that stigma was a significant factor in the early days and, although its impact has lessened, it is still prominent. I have also shown that although mortality rates have declined, thoughts about death are rarely far from people's minds. The oral history evidence points to the positive impact that HIV has had in some people's lives. It has acted as a catalyst for change, encouraging a move towards healthier lifestyle choices. I have also gathered evidence to show that the impact of HIV on sexual relationships has sometimes been detrimental and I have shown how it has led to a solitary lifestyle for some respondents.

I have considered the impact of working in the HIV sector for clinicians and other professionals and have shown that it has changed their professional practice. In particular, I comment on the flexibility that has been necessary to ensure engagement with clinical services by vulnerable and at-risk populations.

I have discussed the experience of ministering within a secular context and have shown that significant elements of ministry - community, sacramental engagement, mission and marking life events - became integrated into the life and witness of Waverley Care. The research evidences the impact of the

⁸⁰ The Church of Scotland HIV Programme supports 27 projects in 15 countries.
http://www.churchofscotland.org.uk/serve/world_mission/hiv_programme/the_church_of_scotland_hiv_programme/hiv_around_the_world

provision of spiritual care within a secular agency, showing that it is possible to create sacred space and to deliver a sacramental ministry within a non-church setting.

I used two models from the field of bereavement to analyse the findings of this research and to reflect on my personal situation. I have shared personal observations and have discussed the impact of HIV on my spiritual journey, using some of the Stations of the Cross as a lens through which to reflect.

Finally, the research shows that Milestone as a place and a community, in tandem with the provision of spiritual care, became a source of hope and love for the people who were most vulnerable and most in need of unconditional care and support.

Recommendations:

(i) Public health

My research shows that there is no clarity about the future trend for infection rates. Monitoring will be required of the source of new infections; in particular, the impact of chemsex will require close observation.

The cohort of people who participated in this research are ageing and have lived with HIV for more than twenty years. Anecdotal evidence suggests that they are at risk of developing co-morbidities at an earlier age than might have been anticipated. Long-term survivors of HIV should be closely monitored. It would be interesting to interview this research cohort in five years' time and to consider any changes in their health and their prognosis. This is a group of people who were described to me by Dr. Scott as 'a forgotten population'. There is a responsibility on those who are charged with their care not to forget.

(ii) The churches

The churches were exemplary in their pastoral responses to HIV when the scale of the problem in Edinburgh was first identified. Historically, the

churches and their members have been generous in their financial support of HIV services. The Scottish Episcopal Church supported the establishment of Positive Help and contributed annually to the costs of the Waverley Care chaplaincy post. Waverley Care was the recipient of Scottish Episcopal Church Bishops' Lent appeals on three occasions, raising substantial funds for the agency. SAFE was supported by the Roman Catholic Church in Muirhouse. The Church of Scotland Women's Guild funded the creation of the Centenary Project and the Presbytery of Edinburgh supported the Waverley Care chaplaincy service for a few years. Church buildings have been made available to host events, for instance the annual World Aids Day gathering at St. John's Church, Princes Street. Since then, church involvement has declined significantly. None of the local agencies has active links with a faith community, although volunteers from those communities continue to offer help and support. The Scottish churches must consider the message that they are conveying to people living with HIV in the current climate. If they believe that there is still an imperative to support vulnerable and stigmatised people in their community, they should seek ways to continue to offer and finance that support.

HIV has challenged the churches to examine their responses to questions of human sexuality and difference. Churches should be encouraged to continue to explore these questions, recognising that there is still work to be done, and should seek ways to offer an inclusive welcome.

(iii) Waverley Care

I have evidenced in this thesis the value of spiritual care within the provision of support and care services for people living with HIV. Waverley Care must now take responsibility for its decision to cease employing a dedicated spiritual care worker and find alternative ways to offer appropriate provision. I caution against entering into an arrangement with a local church. The evidence in this thesis shows that the true value of chaplaincy lies in its embeddedness within the organisation. The ministry of presence is an important element that cannot be replicated. Historic experience would support my contention. At one stage, the Roman Catholic Church made its contribution to the services at Milestone by making a priest available to the

community. He visited weekly, making his presence known by having lunch with staff and service users. There was little real engagement or connection made - weekly visits were inadequate for building relationships and when the Roman Catholic service users died their funerals were inevitably conducted by the chaplain who was known, rather than the priest who was not.

(iv) Further research

I have recommended at (i) above that colleagues concerned with public health should monitor the impact of chemsex. My existing knowledge would suggest that there may be a link between sexual risk taking (including the use of chems) and self-stigma emanating from the negative rhetoric that is shared by some faith leaders. There is a place for research with men who choose to use chems, seeking to explore their spiritual health, to consider whether they have, for example, internalised homophobia or whether they are trying to be someone other than the person God made them to be. There would be a real value in undertaking such research over the next two or three years.

This research limited itself to people who were diagnosed with HIV before effective treatment became available in 1998. It would be valuable to conduct a similar study using the same methods - oral history as a means to gather data and phenomenology as a research tool. Further work could then be undertaken to make a comparative study, exploring the impact of HIV on individuals before and after 1998. One aim of such a study would be to consider the weight given by people to their prognosis at the time of diagnosis.

Concluding Remarks

This research project has allowed me to share deep and meaningful personal narrative from a range of voices. I have shared learning from my experience of ministry within Waverley Care. In particular, I have shared the impact of this experience on my understanding of the holistic and inclusive nature of God.

Robert Kennedy in his book *Zen Gifts to Christians* expresses it in this way:

We believe we are made in the image of God: we know we are one with God, not identical but not separate. How can we believe God created us in God's own image if God can in any way be separate from us? We do not believe that God is only in heaven and we are on earth, and that we relate to God as one who is outside ourselves. Instead, believing that the world is a manifestation of God, we know that the unity of God and the world, as well as the unity we have in one another are analogous to the Three Persons in the Trinity. God's life is our own: God sees with our eyes; God listens with our hearts (Kennedy, 2004: 69).

In this thesis I have attempted to show, beyond any reasonable doubt, that people living with HIV are people made in the image of God, people from whom I have learned something about the nature of God. My hope is that the reader has been both challenged and blessed by reading the narratives that form the heart of this document.

Appendix 1: Research participants

People living with HIV:

Annie: Interviewed 20:01:2016

Astrid: Interviewed 18:08:2015 & 18:11:2015

Michael: Interviewed 14:08:2015

Peter: Interviewed 24:04:2015

Sean: Interviewed 13:08:2015 & 9:3:2016

Clinicians:

Dr. Dan Clutterbuck, Consultant physician Chalmers Sexual Health Centre:
Interviewed: 14:12:2015

Dr. Mike Jones, Retired physician, Infectious Diseases Unit, Western General
Hospital: Interviewed 28:4:2015

Dr. Gordon Scott, Consultant physician, Chalmers Sexual Health Centre:
Interviewed: 7:1:2016

Dr. Philip Welsby, Retired physician, Infectious Diseases Unit, Western General
Hospital: Interviewed 14:4:2015

Waverley Care staff:

Jackie Cameron, Community Outreach Worker: Interviewed 23:10:2015

Karen Docwra, Fundraising Manager: Interviewed 9:12:2015

Nichola Frith, Children and Families Service Manager: Interviewed 15:09:2015

Liz Marr: Senior Manager, Milestone: 1:2:2016

Other Interviewees:

Nigel Cook, former director, Scottish AIDS Monitor: Interviewed 2:3:2016

Dean Fostekew, supporter of Waverley Care: Interviewed 21:02:2016

David Johnson, retired director, Waverley Care: Interviewed October 2014

Helen Mein, retired manager, Positive Help: Interviewed 3:3:2016

Jane Millard, retired chaplain, Waverley Care: Interviewed September 2014

Appendix 2: Consent to the use of data

CONSENT TO THE USE OF DATA

University of Glasgow. College of Arts. Ethics Committee

I understand that Marion Chatterley is collecting data in the form of recorded interviews for use in an academic project at the University of Glasgow.

The project is looking at the impact of HIV on the lives of people living with and directly affected by the HIV virus and at the response of Scottish support agency, Waverley Care. The researcher will record her personal theological reflections on the material she has gathered and on her own experience of working with Waverley Care.

Julie Clague, academic supervisor, will have access to the full content of the interviews. She will not have access to the names of participants and will have no means of identifying what has been said by whom. Names will not be used by the researcher during the recorded interviews.

1. I confirm that I have read and understand the Participant Information Sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I consent to my interview being audio – taped. I understand that I have a legal right to be identified as the copyright owner of my interview and to be identified by name.
I would like my contribution to be anonymous / identify me as the contributor (please delete as appropriate).
4. I understand that if I have requested anonymity, no personal names or identifying material will be used during or in relation to the audio recording, and that I will be referred to by a pseudonym in any publication arising from the research.
5. I understand that my participation in this research will not have any influence on my relationship with the researcher or on my ability to access pastoral care and support.
6. All material will be treated as confidential and kept in secure storage.
7. I understand that quotations from the interviews may be used in future publications, both print and online.

I agree to take part in the above study.

Name of Participant

Date

Signature

Researcher: Marion Chatterley. 104472c@research.gla.ac.uk

Supervisor: Julie Clague. Julie.Clague@glasgow.ac.uk

Department of Theology and Religious Studies. 4 The Square Glasgow G12 8QQ

CONSENT TO THE USE OF DATA

University of Glasgow
College of Arts Research Ethics Committee

Participant Information Sheet*Study title and Researcher Details***Title of Project:**

Reflections on the impact of and response to HIV in Edinburgh: exploring the influence on the lives of people living with and directly affected by the HIV virus and the response of Scottish support agency, Waverley Care.

Marion Chatterley, Spiritual Care and Faith Communities Co-ordinator, Waverley Care and post graduate student, University of Glasgow.

Invitation paragraph

I am inviting you to take part in my research. I am writing about HIV in Edinburgh, looking at the impact of the virus on people who are infected and/or directly affected. I hope to discover some new learning for people who have not been affected by HIV.

Before you decide whether to take part, you need to know how this will work and what you are being asked to do. A member of Waverley Care staff will discuss this with you before you make a decision to participate. You can ask me or that member of staff about the project. There is no requirement for you to take part. Your decision will not affect your relationship with me or with other staff in Waverley Care and will not have an impact on your care.

What is the purpose of the study?

I hope to tell the stories of people who live with and are directly affected by HIV in Edinburgh, and to help other people understand how important this virus has been in people's lives. I want to share your stories and the learning I find in them, especially with people who are interested in spiritual reflection. I will do my own spiritual reflection on the stories I hear and on my personal experience of working with people who are HIV positive for more than 25 years.

I am recording conversations with people where I will ask about the change that HIV has brought to them. I'm interested in positive and negative change. When I write up my final document, I will use quotations from these interviews. They will be anonymous – no-one will know who said what. I will be looking for themes in what different people say in order to be able to share something about the change that HIV has brought to people's lives.

Why have I been chosen?

I'm recording stories from different groups of people to give as big a picture as possible. I know enough about your story to think that it will tell people something important.

Do I have to take part?

No. This is an invitation and you are under no obligation to take part. I am happy for you to make a decision either way. If you decide not to take part, you do not need to give me the reasons.

What will happen to me if I take part?

We will meet, either at Waverley Care or somewhere that you have chosen and I will ask you some questions. I will record the meeting that we have. I am interested in your personal story so there are no fixed questions, I just want to give you an opportunity to tell me about your life with HIV. I'm especially interested in any difference that HIV has made to you. You will be able to stop the recording at any time. If you say something that you don't want to be used, you can tell me and I will remove that section from the tape.

Will my taking part in this study be kept confidential?

Some people will need to know that you have taken part. My line manager, Martha Baillie, will know the name of everyone who has agreed to take part. The member of staff who will discuss the project with you will know that you have been asked to take part. No-one else within Waverley Care will know who has agreed to be interviewed. My supervisor at the University will not know your name or personal details.

Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

What will happen to the results of the research study?

I am writing a dissertation for my Doctorate in Practical Theology. The final work will be examined by the University and an external examiner. It will then be stored in the University Library and will be available on line. It is possible that some sections of the study will be published in academic journals.

Who has reviewed the study?

The work is being overseen by my supervisor, Julie Clague, who is at the University of Glasgow. The permission to do this interview has been given by the University College of Arts Ethics committee.

Contact for Further Information

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Martha Baillie Martha.baillie@waverleycare.org

Dr Marc Alexander (College of Arts Ethics officer) marc.alexander@glasgow.ac.uk

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