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PROMOTING EMPLOYMENT IN YOUNG-ONSET PARKINSON'S DISEASE: A STAGED INTERVENTION APPROACH

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PhD

2010

PROMOTING EMPLOYMENT IN YOUNG-ONSET PARKINSON'S DISEASE: A STAGED INTERVENTION APPROACH

ANGELA BIRLESON

A thesis submitted in partial fulfilment of the requirements of University of Northumbria at Newcastle for the degree of Doctor of Philosophy

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ABSTRACT

This study investigated the employment experience of younger people with Parkinson's Disease (PD). The aims of this study were formulated from reflections on clinical practice and observation of the often detrimental impact caused by relinquishing employment.

A steering group consisting mainly of younger people with PD was established to guide the project. A sequential transformative research design was chosen and three methods of data collection were utilised in a flexible, multi-method approach: a questionnaire, which was distributed nationally and in electronic format via the Parkinson's Disease Society website; a series of three focus groups; and an electronic proforma which recorded the employment stories of respondents via a newly created website. The meaning that employment had for younger people with PD, benefits of working, the decision making process regarding leaving work, difficulties encountered and successful strategies used by younger people with PD to maintain their employment were explored.

This study unveiled a narrative surrounding the experience of employment of younger people with PD. The results indicated that this group required targeted assistance to enable them to maintain employment. The results were therefore transformed into a seven staged intervention to facilitate the maintenance of employment and to alter the current narrative. The staged intervention was developed to address the key issues highlighted by the study.

Respondents identified a lack of available information and had a poor awareness of employment rights. There was a consensus regarding difficult symptoms to cope with in employment with fatigue having the biggest impact and other symptoms being: cognitive changes, stress, anxiety, reduced dexterity and mobility. Lack of flexibility by employers was noted to contribute to difficulty in work, and dealing with customers or speaking in public were the most problematic work roles. Respondents identified the benefits of work as: mental stimulation, a sense of identity, self esteem and financial benefits, and felt that giving up work would contribute to a social withdrawal.

Respondents found that interaction with non-specialist professionals, in relation to the maintenance of work, was ineffective. The study recommends that this intervention should be delivered by a specialist occupational therapist with access to the skills of a multi-disciplinary team. The intervention was tested in practice and an evaluation model was presented to enable further development.

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ACKNOWLEDGEMENTS

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DECLARATION

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work.

Name:

Signature:

Date:

Terminology

In this thesis Parkinson's Disease is referred to, and abbreviated to PD. The Parkinson's Disease Society prefers the term Parkinson's however, in medical and allied health professional literature, the condition is referred to as PD. A choice was therefore made to keep to the term 'PD' throughout the thesis.   The term occupational therapy has been abbreviated to OT, however to aid clarity the term occupational therapist (also sometimes shortened to OT), has not been abbreviated. Wherever possible the term patient has not been used. Although this term regularly appears in medical literature, it is not appropriate in the context of this thesis, so, the term people with PD has been chosen.

At the time of writing this thesis the Parkinson's Disease Society had recently been renamed Parkinson's UK.

1 Introduction

1.1 Reflection on current practice

Speak to any working person over the age of 40 and they can usually describe in great detail their plans for retirement. But, between then and the often yearned for retirement, the more immediate day to day concerns often involve progressing up the career ladder, paying bills, juggling family commitments, and trying to fit in leisure activities and maintain some form of social life. This can feel like a balancing act at the best of times but, when a person is diagnosed with Parkinson's Disease (PD), this balancing act starts to become increasingly unstable. Many people with PD find it difficult to maintain their employment and the longed for retirement comes rather suddenly and, in most cases, without the required finances. Becoming unemployed typically brings with it more than just financial problems; losing the roles associated with being employed can lead to reduced self-esteem and a decrease in quality of life (QOL). As a neurological occupational therapist with a special interest in PD, I have observed both the struggle that people with PD have to maintain their employment and the negative consequences of relinquishing their employment.

Most people with PD have difficulty in accessing services to assist them with maintaining their employment, although there are some government funded schemes that are appropriate for people in this situation. In most locations, health services for people with PD tend to be primarily aimed at older people, and often younger people lack relevant information and services targeted to their condition. Employment services often focus on people who are already unemployed and in receipt of unemployment benefits rather than on people who are trying to retain their jobs. Rehabilitation schemes for unemployed people with health problems promote return to work for people with mental health or musculoskeletal problems; they lack the specialist knowledge to support people with neurological conditions.

In my clinical practice I have observed that people with PD who have become unemployed tend not to replace employment with other activities that would be beneficial to their symptoms. Without the impetus to leave the house for employment purposes, they lose a structure to their day, become less physically active and

experience social isolation. It is usually only at this point that people with PD are referred to therapy services, much later in the course of their condition than the therapists would prefer.

Employment can provide mental stimulation, a need to be physically active, and demands social interaction with others. The symptoms of PD include a deterioration of motor function including mobility, cognitive functioning, speech, and the development of anxiety and depressive symptoms. I have noticed that these symptoms are exacerbated and accelerate when a person with PD leaves their job. An exacerbation of symptoms, a reduction in finances, a reluctance to engage socially and, often, a change of roles within the family can have negative consequences on relationships, confirming that a progressive condition does not only impact on the individual but can have major repercussions for the whole family.

Frequently, people with PD who relinquish their employment have informed me that they later regret their decision. I have often heard unemployed people say that they felt that they 'had' to give up work, that they 'had no other option' but, when asked why they gave up, will often struggle to give a reason other than, "I've got PD, I had to leave". This narrative encourages people to feel like victims of their circumstances and, in a progressive neurological condition where they are constantly challenged to develop strategies to cope with their deteriorating condition, promotes a learned helplessness. Often, employment is the first problem area for younger people with PD. How they deal with this can establish a pattern for dealing with future problems delivered by this progressive condition. Managing to cope with difficulties encountered in the work place can establish an active problem solving approach and promote a sense of control over the condition.

Taking these factors into account, maintaining employment could potentially have a positive impact on the symptoms of PD, and a subsequent positive effect on family relationships, and could set a precedent for using active coping strategies to deal with difficulties in the future. However, the lack of services, information, rehabilitation and support creates a struggle for younger people with PD who wish to maintain their employment. I have noticed that people do not know where to go to for help and tend to ask advice from the professionals that they encounter in the early stages of their condition, such as their neurologist, GP or Parkinson's Disease Specialist Nurse (PDSN). A considerable number of people with PD do not disclose their diagnosis to

their employer and so do not seek help from their manager or Human Resources Department. The internet can provide information on government funded schemes, some of which are relevant to people with PD, but these schemes are staffed by generic staff who have no knowledge of PD and so are unable to advise on difficulties caused by the unique symptoms. Assistance with maintaining employment needs to come from staff with specialist knowledge of the condition who can readily be accessed by the person with PD in the early stages of their condition.

Occupational therapists are well placed within healthcare settings to provide intervention related to employment. Occupational therapists value occupation as both a means to achieve health and a measure of health. They believe that well-being is achieved by engaging in a range of activities meaningful to the individual; an inability to engage in those activities, or a reduction in activity levels, can have a negative impact on the well-being of the individual. Occupational therapy (OT) enables a person with activity limitations to engage in activities by providing intervention to improve their performance, adapt the activity, build knowledge or change attitudes. Occupational therapists consider the individual's ability to participate in activities by asking, "What do you need to be able to do?" rather than focusing on symptoms, and they measure a successful outcome in terms of a reduction in disability. Referral of people with neurological conditions to a neurological occupational therapist is usually via the PDSN or the neurologist, so access should be relatively easy. However, I have come across two barriers to referral in the clinical setting. First, medical staff often limit their intervention for people with PD to consideration of symptom management and not of the wider impact of those symptoms on an individual's life. Symptom management is considered in isolation and not in relation to the wider context of the individual's need or desire to engage in activities. Frequently people with PD have informed me that when they have mentioned to their neurologist that they are experiencing difficulties at work they have been advised to give up work, with no discussion of whether they should, or indeed how they can, retain it. The second issue is that, although occupational therapists have the skills to provide intervention regarding employment, unfortunately within a health service setting their core business is often to promote self-care and facilitate a safe discharge from hospital. Although viewed as important, performance of other activities such as employment or leisure is given little practical consideration. The reflections of my clinical experience and my observations of the current situation for younger people with PD were formulated into a conceptual framework (Figure 1) which

indicated both the need for, and the timing of the provision of intervention to maintain employment. However, currently such an intervention for people with PD or other progressive neurological conditions does not exist. Relinquishing employment has a negative impact both on the symptoms of PD and on the psychological approach to this condition. Younger people with PD are faced with considerable difficulty when trying to retain their employment, and yet there are no readily available sources of support or specialist intervention to assist them. Occupational therapists possess the skills and beliefs to enable people with PD to maintain their employment but usually give little consideration to employment due to priorities and pressures from the services in which they work. This leads me to ask if my reflections are relevant to a wider population of people with PD, and, if an occupational therapist were to provide an intervention to support employment, what would this intervention consist of?

1.2   Aims of the study

The aims of this study were formulated from my reflections on current practice and the impact of leaving employment on younger people with PD. To achieve these aims an investigation of the employment experience of younger people with PD was undertaken. As an occupational therapist I was keen to explore the meaning of employment for this group and to identify if people with PD considered maintaining their employment to be beneficial to their condition. In order to begin to understand the type of intervention that younger people with PD required to enable them to retain their employmen,t I needed to appreciate their decision making process around staying in or leaving work. Identifying the successful strategies used by younger people with PD to maintain their employment would also contribute to this understanding.

Therefore the aims of this study were:

1) To understand the employment experience and trajectory of younger people with

PD

2) To model an intervention to assist people with PD to maintain employment.

To achieve these aims, the following objectives were set:

i) Explore the meaning of occupation for younger people with PD

ii) Identify the aspects of work that may be beneficial to someone with PD

iii) Understand the strategies used for maintaining work by people with PD

iv) Appreciate the decision making process utilised by younger people with PD when choosing to remain in or leave work

Achieving these aims and objectives will lead to a deep understanding of the current employment experience of younger people with PD. Exploring the meaning of work for this group and identifying if work was good for health would indicate if intervention was required to enable younger people with PD to retain their employment. The format and content of that intervention would be informed by the decision making process regarding staying in or leaving work and by identifying specific barriers encountered, and strategies used for maintaining employment by younger people with PD.

1.3   The study

As an occupational therapist used to ensuring that my practice is client-centred I am concerned that any research project should follow a similar ethos. The research had to be of importance and meaningful to younger people with PD, and in addition, it was vital that this group were involved in the study design. A methodology was therefore required that was guided by younger people with PD. To initiate user involvement in the project, a meeting was set up with a newly formed support group of younger people with PD to discuss the pertinence of the issue of employment. The people attending this meeting defined issues regarding employment that were significant for them and, furthermore, confirmed the need for intervention to assist them to maintain employment.

When the importance of this study had been established with subjects, funding for the project was sought through various grant applications. An application to the Parkinson's Disease Society (PDS) was successful. A steering group, consisting of younger people with PD, relatives and a PDS staff member was created to guide the development and implementation of the research project. One of the conditions of this grant was the creation of a web-based information resource developed as an output of the study. This resource was to be developed in partnership with the PDS and hosted by their own web-site. The web-site was to be informed by data gathered in the study and was to be used as a resource for younger people with PD for advice and information on employment

issues. In order to satisfy the conditions of the grant the data collection phase was followed by production of a web-based information resource (appendix O). The collected data were then analysed in relation to the research aims and objectives of this study.

1.4 Chapter Descriptions

As the chapters unfold, an iterative process of returning to review and reflect on the aims and objectives of the study ensures that it continues to be focused. This will also serve to direct the reader from one chapter to the next.

Chapter One describes the context in which the study was developed. Observations and reflections from the researcher's clinical practice identified the scope of this study, these were then translated into the study's research aims and objectives.

In Chapter Two the framework of contemporary evidence that is required to explore the aims of the study is established. Specific PD symptoms are examined to understand potential barriers to the maintenance of employment for people with this condition. Typical management strategies are drawn from the literature including an examination of the impact of self-management. Current OT practice for people with PD is considered and the appropriateness and efficacy of OT for this client group is examined. Existing assistance available for the maintenance of employment for people with progressive neurological conditions is investigated to discover why this assistance is inadequate and fails to meet the needs of this population. These key areas of evidence, which underpin and inform the development of the study are critically appraised and the research aims are regarded in light of this appraisal.

In Chapter Three the theoretical framework and philosophical assumptions that encompass and guide the design of the study are portrayed alongside a description of the methodological approach taken to the collection and analysis of data and the validity procedures. A sequential transformative research design was chosen for this study, taking into consideration the exploratory nature of the research initiated by a clinical question. This design takes into account both the lives of younger people with PD and the profession of the researcher and permits a flexible, multi-method approach to the collection of data, thus allowing developments to be incorporated into an emerging

research design. In this chapter the validation trail is introduced, re-emerging as it does in each subsequent chapter.

Chapter Four details the four phases of data collection and analysis used in the study. The three methods of data collection were: a questionnaire, which was distributed nationally and in electronic format via the PDS website; a series of three focus groups which took place in South Yorkshire and the Midlands; and an electronic proforma which recorded the employment stories of respondents via a newly created website.

The first phase includes the establishment of a steering group consisting mainly of younger people with PD, the ethical approval process and piloting the questionnaire. The second phase describes the distribution of the questionnaire and the sources and descriptions of the questionnaire respondents. Phase three discusses the rationale for the selection of focus groups as a data collection method, describes the planning and implementation of the groups and outlines the emerging themes.

In the fourth and final phase of data collection, a contextual portrayal of the participants' experience of employment was sought using a unique instrument that both captured this experience and was grounded in the views of the participants. This tool was created using the themes gathered from the first three phases of data collection and through consultation with the steering group.

In this chapter the analysis procedure applied in each phase of the data collection process is described and initial results presented.

In Chapter Five, the results are presented using a novel approach. Since the study was directed by a clinical question that was influenced by the professional beliefs and practices of the researcher, the results of the data analysis have been transformed into a staged intervention to facilitate the maintenance of employment for younger people with PD. The chapter presents the seven stages of the intervention in sequential order. Each stage uses a similar format consisting of four parts which include the researcher's clinical reflections, data from the study, supporting theory from the literature and, finally, a description of the intervention carried out in that stage.

The final chapter considers the extent to which the research aims and objectives have been met and highlights the understanding gained through undertaking this study. Some key issues that have been identified by the research process will be discussed. Finally

the chapter explores the use of an evaluation model to identify further development of the intervention.

Figure 1 - Emerging Conceptual Framework

Personal theory –> Tacit theory

Symptoms of Parkinson's experienced prior to diagnosis

Initial problems experienced in employment – unable to engage effective coping strategies

Physical symptoms experienced – Parkinson's diagnosed

Unable to adapt employment role due to symptoms of depression, apathy, lack of coping strategies or difficulties with cognitive set-shifting

Intervention needs to be provided at these points to encourage the development of coping strategies

Loss of active and social leisure activities due symptoms of depression, apathy, lack of coping strategies or difficulties with cognitive set-shifting plus emerging physical limitations

Referral to therapy services due to increasing disability. Employment and social roles already lost, aim of therapy to maintain mobility and self-care activities.

Social isolation experienced by individual and family, and lack of meaningful structure to the day increases depression. Lack of physical exercise exacerbates disability caused by physical

Free time available from employment and leisure roles relinquished not filled by active or social activities

2 Review of Literature

2.1 Introduction to literature review

This chapter explores the literature to establish the need for, and the scope of, an intervention to support the maintenance of employment in younger people with PD. There are wide ranging factors that impact on both the experience of, and the maintenance of, employment and therefore this chapter will consider the literature regarding a range of issues that relate to employment in order to set the context. In addition, a closer examination of the literature relating specifically to vocational rehabilitation or interventions to maintain employment for people with PD will be undertaken. The literature considered in this chapter will be revisited in Chapter 6 when it will be used to support the data analysis.

To set the context a brief overview of PD is given, including the incidence and prevalence. The psychological symptoms and the social impact of the condition are then described. The review then considers how PD, is currently managed from a medical perspective, followed by closer exploration of the non-medical management of psychological symptoms. The role of self-management is explored, including current approaches and the influence of empowerment. The relationship between occupation and QOL is then investigated and a summary of the current situation regarding employment for people with PD and similar conditions is given, including relevant legislation. The literature presented in the first part of the chapter was found following a search of these data bases: Cinahl, Medline, AMED, Web of Science, Cochrane Library, Proquest and National Library of Guidelines. The years searched were limited to 1990-present however a search of the references cited by these articles highlighted some key texts from the 1980s which were included. The terms 'employment' and 'disability' were used in the search engine Google which highlighted many internet sites concerned with employment legislation for people with disabilities. These sites then enabled a more detailed search of relevant legislation and policies to be undertaken. The chapter then undertakes a detailed review of the literature surrounding employment and PD and occupational therapy and PD. The focus here is to establish contemporary opinion regarding interventions, current and potential practice and the identification of factors that should be included within an intervention to maintain employment for people with

PD. The specific search strategy used for this review will be identified within the sub-section.

2.2   An overview of Parkinson's Disease

PD is a progressive degenerative neurological disorder that affects movement and cognition. This condition also affects a person's ability to communicate and carry out activities of daily living, including employment and family responsibilities. Studies have identified that many people with PD experience difficulty in maintaining their social activities and their employment (Chesson 1996, Doherty 1991).

Currently, there is no cure for PD and it is managed with a combination of drugs, non-pharmacological therapies and, occasionally, surgery. PD is a disorder of the extrapyramidal system, which occurs following the loss of 50% of dopaminergic neurones within the basal ganglia (MacPhee and Steward 2007). Currently, the cause of PD has not been identified indeed, PD may be a collection of conditions, each with a different cause. However, both genetic and environmental factors are referred to in the aetiology of this condition (Calne and Langston 1983, Gibb and Lees 1988, Schapira 2006).

Making a diagnosis is problematic as the differential diagnosis for PD is wide ranging and the diagnosis itself remains clinical and is best undertaken by a specialist. Initially, the cardinal features are used for diagnosis including resting tremor, bradykinesia, rigidity and an asymmetric onset (Bhatia et al 2001). Usually, an optimal response to L-dopa, supports a diagnosis but this is not universal. Certain positron emission tomography (PET) techniques can assist the diagnosis but are not recommended for routine use and, most importantly, regular review of the response to treatment should be seen as part of the diagnostic process (Bhatia et al 2001). Often, the person with PD has waited with an uncertain diagnosis for some time as only this regular review can confirm diagnosis in most cases (Bhatia et al 2001).

Difficulties with diagnosis also affect the calculation of incidence and prevalence of the condition. Prevalence rates range between 108 and 164 per 100,000 (Clarke 2001), some studies indicating two per 1000 people overall but up to two per 100 of the elderly population (PDS 1999). One in seven people with PD will be diagnosed under the age of 50, and one in 20 of those diagnosed will be under 40, indicating that there are

around 6,000 people with PD who are under 40 in the UK and 30,000 people of working age (Morris 2003).

Some studies have indicated that there is more than one type of PD and these types are defined by age-related boundaries. However there is some dispute in the literature as to how these different types are defined. The PDS defines Younger Parkinson's as those who were given the diagnosis between the ages of 21 and 45 but who are currently under 65 (PDS 2001). Young Onset Parkinson's Disease (YOPD) is defined as onset at age 21 to 40, Juvenile Parkinson's (JP) as onset before age 21 (Morris 2003, Quinn et al 1987), and older onset or Lewy Body Parkinson's, as onset at over 40 years. JP in itself is thought to represent a range of pathologies and is a condition that is distinguishable from onset over the age of 20 with a higher occurrence of familial Parkinsonism (Schrag et al 1998, Pantelatos and Fornadi 1993). Although studies have indicated that YOPD and older onset/Lewy Body Parkinson's are essentially the same condition on an age related spectrum, differences have been reported in terms of symptoms, disease progression and prognosis, and also the time at which complications related to L-dopa appear (Schrag et al 1998, Pantelatos and Fornadi 1993). These findings indicate two sub-types of PD, the earlier onset being predominantly a motor disorder and the later onset associated with greater mental deterioration (Schrag et al 1998). The predominant motor disorder of YOPD includes motor fluctuations (particularly in response to L-dopa) and a significantly higher rate of abnormal voluntary movements or dyskinesias occurring frequently and early in the course of the condition (Pantelatos and Fornadi 1993, Schrag et al 1998). However, some studies argue that differences between younger and older onset are explained by physiological changes or age related factors that are unrelated to the disease itself (Pantelatos and Fornadi 1993), as younger people with PD are more challenged than older patients by psychosocial issues such as loss of employment (Calne et al 2008).

Only 46% of people with PD under the age of 42 have been found to retain employment (PDS 2001) and only 16% of people with PD of working age remain in employment (Martikainen 2006). In an earlier study, it was found that only 11.8% of people with PD continue to work until retirement age (Doherty 1991), with people retiring or leaving work on average six years earlier than originally intended (Martikainen 2006) and 10 years following the onset of the condition (Shrag and Banks 2006).

2.3 Psychological symptoms

Although often classified as a movement disorder, PD is associated with a wide-range of non-motor symptoms, the most common ones being depression, cognitive impairment, psychosis, anxiety, fatigue and sleep disorders. It is estimated that anxiety, depression and fatigue occur in between one third and half of all patients (Sullivan 2007, Shulman et al 2002, Kostic et al 1994).

Depression is the most frequently occurring non-motor symptom in PD, although there is a wide variation in the estimates of its frequency, ranging from 20% to 70% (Hantz et al 1994, Schrag et al 2000, Meara 1999), which compared with 7% of the general population (Bunting and Fitzimmons 1991). Currently, there are no validated screening or diagnostic instruments for depression in people with PD, therefore research in this area is fraught with methodological difficulties.

Depression may be the first symptom that presents in PD (Shulman et al 2002), emerging before the motor symptoms, and may be an indicator or marker of the condition (Shiba et al 2000). Depression occurs more frequently in PD than in other similar chronic conditions (Bhatia et al 2001) although the cause of this is under debate. Some studies suggest that depression has a neuro-chemical basis, others indicate that it is influenced by the person's perception of handicap or loss of life roles. No significant correlation has been found between the individual motor features of PD (bradykinesia, rigidity and tremor) and the frequency and/or severity of depression (Schrag et al 2001). However depression has been linked with limitation of activities of daily living (Kostic et al 1994). Even though younger people tend to have lower disability scores than older patients, they have been found to have higher rates of depression (Santamaria et al 1986, Starkstein et al 1989, Jenkinson et al 1999), perhaps indicating their higher expectation of function than an older person or problems of adjustment rather than to the disease per se (Jenkinson et al, 1999). Depression in PD is more strongly influenced by the patients' perceptions of handicap than by actual disability and is associated with advancing disease severity, recent disease deterioration and occurrence of falls (Schrag et al 2001). Depression can be more debilitating to the individual and family than lack of physical function and is reported to be under-recognised in people with PD (Burn 2002).

Anxiety is a common non-motor symptom associated with PD and has been found by some researchers to occur in a higher percentage of people with PD than depression. Over one third of people with PD suffer from anxiety (Jones et al 1999) and up to 40%

of patients demonstrate symptoms that fulfil the criteria for an anxiety disorder (Marsh 2000, Menza and Dobkin 2005).

As with depression, anxiety is often present before the onset of motor symptoms (Ishihara and Brayne 2006) and can be more disabling than the motor symptoms (Marsh 2000). Anxiety in people with PD has been linked to their fears about managing the condition and about physical deterioration in the future (Lloyd 1999), but most studies indicate that it is part of the neurodegenerative process (Marsh 2000, Erdal 2001, Menza and Dobkin 2005, Uhrt and Aarsland 2005). There is some debate in the literature as to whether anxiety is linked to motor fluctuations (Menza and Donkin 2005): although there is a positive correlation for some people with PD (Erdal 2001), some studies have found them to be more typically unrelated (Richard et al 2001). In addition, anxiety has not been found to be linked with the severity of disability or motor symptoms (Mondolo et al 2007), although some studies indicate the involvement of lack of control over symptoms and learned helplessness (Erdal 2001). As both anxiety and depression are often experienced during the early stages of the condition by people of working age, they could contribute to both the ability to engage in employment and the ability to develop coping strategies to manage the physical and social symptoms which may impact on employment.

Additional non-motor symptoms include sleep disorders, fatigue and apathy. Many people report that their sleep pattern has been reversed, sleeping during the day and remaining awake at night. Many report falling asleep in the early evening and waking in the early hours of the morning. In some cases, fatigue is linked to insomnia but in other cases it would appear to be unrelated to a lack of sleep but either linked to the increased cognitive and physical effort involved in performing everyday activities, or associated with the off state (Witjas 2002). The off state or 'on-off' effect occurs in patients who have received levodopa therapy for a prolonged period, which leads to rapid fluctuations in motor performance from a mobile state to a rigid state (Marsden and Parkes 1976). Fatigue has been noted in up to 81% of people with PD (Havlikova et al 2008a), however, neurologists often fail to recognise sleep disturbances in patients (Shulman et al 2002). Fatigue is influenced by the presence of depression, the worsening of mood disorders and poor physical function (Havilokova et al 2008b). Severe anxiety has been found to contribute significantly to daytime somnolence (Borek et al 2006). Apathy has recently come to be associated with PD and is seen to be not simply a reaction to the symptoms but a true feature of this condition, with one study

estimating the prevalence in the PD population as being between 16.5% and 42% (Pluck & Brown 2002). Apathy is defined as

> *"a constellation of behavioural, emotional, and motivational features including a reduced interest and participation in normal purposeful behaviour, lack of initiative with problems in initiation or sustaining an activity to completion, lack of concern or indifference, and a flattening of affect."* (Pluck & Brown 2002, p636)

In relation to employment, the most interesting results in this study concerned the relation between apathy and cognition. People with high apathy levels performed below the level of those with low apathy on various measures of executive function. Difficulties associated with executive function or cognition included disordered thought and memory (Pluck and Brown 2002).

PD is associated with specific cognitive deficits that are quite separate from dementia, and these have been found to occur within one to two years of onset (Klepac 2008 et al). Typical cognitive impairments include executive dysfunction, impaired attention, learning deficits and memory impairment (Tamaru 1997, Ehrt and Aarsland 2005, Piovezan et al 2008). People with PD display attentional deficits that have been found to predict subsequent cognitive impairment (Taylor et al 2008). The specific attentional deficit relates to set shifting (Owen et al 1992) and research indicates that, although people with PD present with what would typically be referred to as dysexecutive syndrome, the actual problem lies in set shifting rather than with problem solving (Zgaljardic et al 2003). This set-shifting deficit has been found to be a primary cognitive impairment in PD and is thought to arise from a dysfunction of the nigrostriatal-dorsolateral prefrontal cortex complex loop (Cronin-Golomb et al 1994). Conversely, some researchers have found that people with PD are able to shift from one idea to another but have difficulty generating ideas (Wilson et al 1992), while further studies indicate that counterfactual thinking is impaired in PD. Counterfactuals are important in problem solving functions such as planning, causal reasoning and decision making, and this impairment is thought to be linked to frontal lobe dysfunction (McNamara et al 2003).

Dementia is commonly associated with PD. Its prevalence has been stated as being 44% in people with PD over the age of 60 (Hobson and Meara 1999) but occurs less frequently in the younger person, with age being the primary influencing factor in prevalence (Schrag et al 1998). Due to the positive correlation between age and dementia, no further consideration will be given to this relationship.

Better cognitive performance is associated with improved quality of life (QOL) and there is evidence of increased incidence of depression in people with executive functioning impairments (Klepac et al 2008). Despite the wide range of non-motor symptoms being common, many studies point to the lack of recognition and underassessment of these symptoms, with neurologists failing to recognise depression, anxiety and fatigue more than 50% of the time and failing to recognise sleep disorders in 40% of patients (Shulman et al 2002). Both the motor and non-motor symptoms of PD could affect a person's ability to carry out employment related activities, with some people reporting that the non-motor symptoms are more disabling than their motor symptoms (Witjas 2002).

2.4 Social impact

The social impact of PD is considerable and seems to differ from that of other progressive disorders. People with PD report that they feel inclined to retreat from social situations due to their embarrassment in situations in which they are required to walk, talk or eat (Nijhof 1995, Reese 1999). PD has been associated with feelings of shame and stigma and a perceived lack of social competence. Stigma is a problem reported particularly by younger people with PD (Schrag et al 2003). A Dutch survey indicated that one in four people reported feeling embarrassed by their illness (de Boer et al, 1999), whilst a British survey found that 42% of people felt embarrassment due to their PD symptoms with 48% of them reporting a need to avoid public situations (Peto, Fitzpatrick & Jenkinson, 1997).

Communication, which is required for social engagement is commonly affected in people with PD (Deane et al 2003a, Heberlein and Vieregge 2005) and may lead to social isolation (De Angelis 1997). Reduced intensity of vocal utterances, reduced vocal expression and a mask like face can interfere with social interaction and communication (Tickle-Degnen and Lyons 2004), however even when the changes to speech do not impair intelligibility people with PD can feel a negative impact on their ability to communicate (Miller 2006). Pragmatic communication skills in social situations have been found to be impaired in people with PD and are thought to be linked to frontal lobe dysfunction (McNamara and Durso 2003). Dysarthria or vocal apparatus motor limitations can produce a voice that sounds sad or devoid of emotion (Streifler 1984,

Pell et al 2006) which influences daily living (Miller et al 2006) and is linked to a reduction in QOL (Heberlein and Vieregge 2005).

One in five people with PD live alone and report feeling isolated, with lack of social contact being the most common non-medical problem (Oxtoby, 1982). For most people, their workplace provides the majority of their daily social contacts. Withdrawing from this workplace can severely reduce the person's social network, with the resulting impact being not only on the individual. Wider social networks have been observed to suffer most, in that they tend to be ever decreasing for the person with PD (Schrag, Jahanshahi & Quinn, 2000), and social interaction options are lessened for both the person with the condition and their carer (Robertson 2008). Unfortunately, this results in increased pressure on close family relationships, which feel the strain of coping with PD in isolation (Jenkinson et al, 1999, Schrag et al 2003). The breakdown of relationships has been attributed to YOPD in some patients (Calne et al 2008). Younger people with PD report that their main concerns regarding the condition are the effects on their family, particularly children, maintenance of employment and the emotional effects of the diagnosis (PDS 2003).

An additional factor associated with the onset of a debilitating condition such as PD is the adoption of a sick-role. There is much work around the classification of disabled people as sick although this view is often challenged. Usually the sick-role runs in parallel with its accompanying illness, being occupied temporarily until the illness subsides (Barnes 1990). However, for people with PD, their condition is progressive and the individual has to make a constant series of adjustments to their life. An individual's self-image, their attitudes and beliefs around health and the importance of work play a part in how they come to terms with and respond to the challenges of their disability (Thomas 1999a). Even if the person with PD does not want to adopt a sick-role, others may impose it upon them, and try to remove their usual rules and responsibilities (Barnes 1990). Within employment it may be difficult for work colleagues to understand that an individual with a progressive deteriorating condition is not sick, and colleagues may struggle to understand how to deal with the situation including how much help they should offer. The person occupying the sick role can begin to accept the dependence offered until their usual roles, responsibilities and obligations are removed from them on a permanent basis.

A report commissioned by the Department of Health (DoH) (2001) identified the core problems experienced by people with chronic disease as: accessing social and other services; managing work and the resources of employment services; accessing chosen leisure activities; developing strategies to deal with the psychological consequences of the illness; and learning to cope with other people's response to their chronic condition. These mostly social difficulties are familiar to people with PD and the report highlights that assistance in dealing with these difficulties has not been forthcoming either from the NHS, social services or employment services.

2.5 Medical management of Parkinson's Disease

The mainstream treatment for PD is currently L-dopa, but this is by no means a magic cure, although some people may find an immediate cessation of their symptoms when first taking a L-dopa preparation. However, this can be short lived due to the severe side effects relating to long-term use and higher doses. It is imperative that medication is monitored by a specialist to ensure optimal symptomatic relief, using drugs such as dopamine agonists, amatandine and anticholinergics (Bhatia et al 2001). The choice of the medication management regime must take the individual's lifestyle into consideration. Ideally, the younger person with PD should delay the use of L-Dopa for as long as possible, as they will have many years of treatment in front of them. However, the demands of their life roles, including employment, may necessitate immediate and full symptomatic relief.

A range of surgical techniques are used in symptomatic relief, until recently pallidotomy being the most widely used. Many of the motor disturbances associated with PD can be reduced by this procedure, but emotional cognitive and behavioural deficits have been reported as side effects (Bhatia et al 2001). Deep brain pallidal stimulation also has been found to have beneficial outcomes in relation to motor symptoms but is associated with cognitive decline in older patients. The best results from sub-thalamic stimulation have been found in people with advanced PD, and this approach has also produced improvements in dyskinesias (Bhatia et al 2001). Unilateral thaladotomy can reduce tremor and rigidity and result in a reduction in the need for L-dopa. It has limited effects on akinesia and is therefore most appropriate for people whose major symptoms are tremor and rigidity. In addition, thalamic stimulation has also been shown to be useful in reducing tremor (Bhatia et al 2001).

Although the management of PD tends to focus on the symptomatic treatment of motor difficulties, non-motor problems, including depression, may have a greater impact on QOL. In clinical drug trials, the Unified Parkinson's Disease Rating Scale (motor section) is used as the primary outcome measure, however this motor performance has been found not to contribute significantly to QOL, indicating that treatment should be expanded to other disease features such as the contribution impairment, disability and handicap has on depression in this condition (Schrag, Jahanshahi and Quinn 2000). The strongest predictor of QOL in PD has been found to be the presence of depression, with other factors being level of disability, disease severity and cognitive impairment (Bhatia et al 2001, Shulman et al 2002). There is evidence that early aggressive treatment of depression may have an impact on the cognitive performance of people with PD, therefore early recognition of behavioural symptoms is important in the management of this condition. The early identification and subsequent treatment of depression and sleep disturbances can significantly improve a person's QOL (Sullivan et al 2007). Despite this, non-psychiatric physicians have repeatedly been shown to recognise depression in only 30-40% of depressed patients in primary care settings (Shulman et al 2002). As depression and anxiety have shown a correlation with sleep disorders, researchers highlight the importance of neurologists to investigate the possibility of their patients having these conditions if he/she presents with a sleep disorder (Borek et al 2006). It has been recommended that all people with PD should receive interventions for cognitive impairments due to the high degree of under-recognition of these symptoms (Klepac 2008 et al). To date, there are no clear guidelines on either the best way to diagnose, or to manage, depression in PD (Burn 2003, Ghazi-Noori et al 2003) and there is little evidence of the efficacy and safety of antidepressant therapies.

2.6 Non-medical management of psychological symptoms

Due to the complications associated with the medical management of PD, the non-medical management of this condition can be an essential component of overall care. As previously highlighted, the disabling effects of PD are not always due to physical impairment (Chesson 1996). Social, psychological and environmental factors have been found to play an important part (Yarrow 1999), and just as in the medical management, the non-medical management intervention is required to deal with these factors in addition to fulfilling the need for high quality information (Jackson and Kelsey 1999).

A retreat from social situations indicates an avoidance strategy found to be associated with higher levels of depression, anxiety and physical symptoms (Ehman et al 1990, Ring 1993). Interventions aimed at dealing with psychological symptoms such as stress, by promoting active coping methods, cognitive restructuring and relaxation can be effective in reducing depressive symptoms and can be integrated with medical treatment (Ehman et al 1990, Ellgring et al 1993). Behavioural intervention has been found to reduce anxiety more than using medication alone (Lundervold et al 2009) and more specifically Cognitive Behavioural Therapy has found to be effective in treating anxiety and depression in PD (Feeney et al 2005). Superior emotional well-being in PD has been found to be positively associated with perceived control over symptoms (but not over disease progression) (Wallhagen & Brod, 1997) and with active (cognitive and behavioural) coping strategies, which in turn were associated with better social support. This active coping has been found to predict function in PD (Schreurs, De Ridder & Bensing, 2000). However, whilst depression has been found to be marginally positively associated with avoidance coping methods (Ehmann et al 1990), it has not been linked with social support. Emotional support, in the form of a sense of social connectedness and encouragement, however, has been found to be to be universally beneficial (Gordy, 1996). Studies measuring QOL in PD have found, almost unanimously, a need for social and emotional support and interaction that has unfortunately often gone unmet (Karlsen et al, 2000; Schrag et al, 2000).

The ability to engage in social activities has been found to represent a QOL marker in the lives of those with PD (Birleson 2002), and yet people with PD rarely receive intervention from statutory services to enable them to maintain these roles. Usually people with PD only receive services when they are in the later stages of this condition, have an acute admission or can no longer remain at home. Guidelines for best practice in the management of PD indicates the involvement of a multi-disciplinary team at each stage of the condition (Macmahon et al 2001) and has been specifically recommended for psychosocial problems associated with YOPD (Calne et al 2008). However access to members of these teams has been found to be limited even though early intervention is essential to instigate prophylactic measures that will delay the development of some of the more distressing symptoms later in the course of the condition (Chesson et al 1999, Thomas et al 1999b). The National Institute for Health and Clinical Excellence (NIHCE) guidelines recommend that people with PD have access to specialist nursing, OT, physiotherapy and speech and language therapy (NIHCE 2006) although in a recent

survey of members only 34% of people had received intervention from an occupational therapist, 54% had received physiotherapy intervention and 37% from a speech and language therapist (SLT) (PDS 2008).

2.7 Self-management and empowerment

Part of the non-medical management of PD that should not be underestimated is the importance of the individual's own role in the management of this condition. Self-management programmes for people with PD are delivered by health providers, usually therapists or Parkinson's Disease Nurse Specialists (PDNSs) or by local PDS support groups. The aims of self-management programmes for people with chronic diseases have been described as a method to enable them to be effective in accessing health and social care services and gaining and retaining employment with the result being improvements in confidence, resourcefulness, self-efficacy and higher self-esteem (DoH 2001). People with PD should be educated to make best use of therapies and social services to empower them to take control by developing strategies to cope with life style changes resulting from this condition (Wright 1999). Such aims in turn may result in a more assertive approach to accessing or demanding appropriate services.

The content of these programmes usually relates to the progression of PD, coping with symptoms, medication issues, and the roles of the various professionals providing intervention in this condition. Although the focus is on education in these groups the support element is also important, with social support having been found to be key in determining functioning in PD (Ehmann et al, 1990). In 2003 the PDS held consultation events for younger people to find out what issues were affecting this group. They identified the key issues pertaining to YOPD as being appropriate information; emotional support; family and relationships; and employment and finances (Morris 2003).

In relation to self-management, having appropriate information in the early stages, and knowing where to go for support, was highlighted as being particularly important. As maintaining employment activities has been identified as a fundamental issue for younger people with PD it would seem appropriate that any self-management programme aimed at this group should focus on this topic. In addition, the accessibility of the programme should be considered in terms of its timing and location and it would

seem imperative that alternative, more flexible sources of education and support are explored.

However, providers of PD self-management programmes revealed that despite these programmes being seen as a popular and effective method of empowerment, the programmes are under utilised by the younger age group and a large number of people with PD have reported not having access to a traditional support group (Peto et al, 1997), being unable to attend or preferring not to attend. A variety of reasons have been offered as being responsible, such as timing of the programme i.e. during 'normal' working hours, a reticence to mix with older people/people in the later stages of the condition, or simply that the content of the programmes are not specifically geared to the needs of younger people and do not cover issues such as employment (Morris 2003). The PDS themselves have had difficulty accessing this younger age group, generally using the PDNS network, but problems are encountered in the areas that do not have funding for these posts. However an ally in the development of self-management is the use of the internet for both healthcare information and support. The number of people who own computers and have access to the internet has increased rapidly in recent years. This is now a common method of exploring healthcare information (Timmons 2001), which is instantly accessible at a convenient time for the user. The internet is also being hailed as an effective method for delivering patient education or self-management programmes (Perbohner 1999, Lewis 1999), and users of on-line support groups have found them useful in promoting self-management. Indeed despite the difficulty in accessing younger people with PD, a website designed and hosted by the PDS for younger people has seen some positive results. In a survey of younger people with PD, chat rooms and bulletins boards were seen as a useful way of contacting this group, particularly as it was not face-to-face (Morris 2003). In a study investigating the use of internet support groups 2 out of 3 participants reported that membership of a PD group had made them more confident when talking to health professionals and able to ask more questions. In addition, nearly half of participants reported making tangible changes in their disease management regimes, including the use of medication which they attributed to advice and information received through membership of an internet group (Turnbull 2001).

Three areas in which the internet has assisted in promoting coping ability have been found to be empowerment, augmented social support, and facilitated helping of others (Gordy 1996, Reeves, 2000). This facilitated helping can give meaning to a person's

experience and a way of achieving mastery over the condition (Reeves 2000). It is interesting to note that mastery or empowerment over the condition has not been found to be related to physical disability. A study has shown a non-significant association between perceived severity and actual physical disability suggesting that younger people with PD base their assessment of severity on factors other than physical factors. Younger people perceive their condition as severe more often than older individuals and perceive that they have little or no control over their symptoms. One of these factors is indicated as being perceived control of the progression of the condition, when control over the condition is perceived by the individual as being non-existent then the severity is perceived as high (PDS 2002).

2.8 Occupation and quality of life

Although the purpose of this project is not to measure QOL it is necessary to examine the relationship between activity and/or roles related to employment with QOL and if employment or occupation makes a positive contribution.

QOL has been described in a variety of ways and is often used as a short hand term for collective well-being (Rapley 2003) however it is currently viewed as individual subjective well-being which comprises of measures of satisfaction, happiness, well-being, self-actualisation, freedom from want and objective functioning (WHO 1991). Other attributes of QOL include perceived freedom, personal integrity, intrinsic motivation and the level of enjoyment attributed to life experiences (Velde 1997, Rapley 2003). The subjective aspect of QOL and the importance of participation and engagement in activities are themes which emerge frequently in QOL definitions. QOL is described as a process of engagement with life and through participation in social activities that are personally relevant and which capitalise on a person's strengths and capabilities (Brown 1997, Rapley 2003). When considering QOL for people with disabilities one of the crucial issues identified by many researchers is the ability to adapt to and accept the condition by changing the way they experience external conditions (Velde 1997, Martin and Thompson 2001). In a study that assessed QOL, disability, depression, and control beliefs (mastery and locus of control), 'mastery' was shown to predict QOL in PD even taking into account depression and disability (Koplas, et al 1999). Measures of empowerment have been found to reflect measures of social participation (Nowotny et al 2004).

Occupation provides a mechanism which allows an individual to adapt and flourish when faced with the need to change (Wilcock 2002). In addition to linking QOL to engagement in occupation, researchers and theorists highlight the need for the occupation to be relevant, interesting and meaningful to the individual and purposeful so that it fulfils their life roles (Fidler 1994, Velde 1997, Wilcock 2002). There have been few studies examining employment in people with PD however there has been a recent surge of interest into employment for people with MS. People who have MS and who are in employment have been found to be more socially active and have a higher QOL (Johnson 2004, Rumrill et al 2004a, Yildiz et al 2006) and similar results have been found relating to people with spinal cord injury (Jain et al 2007).

Occupational deprivation has been identified as a risk to health. The inspection of Welfare to Work for disabled people acknowledged the importance of employment for disabled people *"in terms of self-fulfilment, income and interactions in society"* (DoH 2001 page 1). Purposeful occupation enhances health and the maintenance of well-being (Wilcock 2002). The importance of employment extends beyond financial independence and can allow social interaction, provide a structure to the day and help to maintain positive health and wellbeing (Wilcock 1998, Yerxa 1998, Waddell and Burton 2006, Banks and Lawrence 2006). People with MS have been found to be healthier when they are employed (Johnson 2004); people without a neurological condition if unemployed are more likely to report health problems than those in employment (Steward 1996). In a review of work initiated by the government a consensus regarding the reasons why people with illnesses or disabilities should remain in work proposed that work led to better health outcomes, is therapeutic, reduces the risk of long term incapacity and improves QOL (Waddell and Burton 2006). Loss of employment has been related to depression both in the general population and in people with PD (PDS 2002, Warr and Jackson 1987). This onset of depression is thought to develop where there has been an unsuccessful adaptation to unemployment and individuals have developed a sense of incompetence and despair particularly if there has been a reversal in the main breadwinner role (PDS 2002). Constructive adaptation is seen to be when individuals have tried to remain occupied in social, leisure or voluntary activities (Warr and Jackson 1987).

QOL is increasingly being used as a social indicator for purposes of policy development in the disability service area and is a driving force in health and social care service design and outcome evaluation (Rapley 2003). Low levels of QOL have been related to

high usage of health and social care services by people with MS (McCrone et al 2008). The literature indicates that intervention to maintain employment could not only improve QOL for those with PD but also be cost effective in terms of the prevention of physical deterioration and depression.

2.9 Disability, employment and legislation

Although people with disabilities make up a large and growing proportion of the British working-age population (between 12% and 16%) employment rates among disabled people are low at around 40% (Burchart 2002). For people with neurological conditions the picture is similar, 25-40% of people with MS retain their employment until retirement age (Unger et al 2004) and only 43% of Americans with MS are employed (Unger 2004). Only 23.4% of people with PD under 65 were found to still be in employment in 1998 (1998 PDS) and in a later survey 47% of people with PD under the age of 42 were in employment (PDS 2002). The factors that contribute towards loss of employment are proposed as varied and not just influenced by onset age and disease duration they are complex and are more than symptom related (Schrag and Banks 2006). In a study of people with MS women, older workers, people with low educational levels, people with cognitive impairments or people with physically demanding jobs are more likely to leave employment (Unger 2004). Maintaining employment can be difficult due to the symptoms of PD and other neurological conditions being varied, hidden and fluctuating. A third of people under the age of 42 who had left work since the onset of PD reported that they had been 'let go' by their employer (PDS 2002), and it has been found that people with MS are more likely to file discrimination complaints regarding demotion and a lack of reasonable adjustments than people with other disabilities (Unger 2004).

Of all people who become disabled while in work, one in six lose their employment during that first 12 months. To exacerbate this problem, finding employment is more difficult for disabled than non-disabled jobseekers and one-third of disabled people who do find work are out of a job again by the following year (Burchart 2002).

The past two decades have seen an increase in legislation to promote employment for people with disabilities and to support employment rights. The government believes that, for people of working age, employment is key to economic security and social inclusion following the wide recognition of the links between unemployment, poverty,

and poor physical and mental health. The Disability Discrimination Act (1995) introduced employment rights for people with disabilities in 1996. The act makes it unlawful for all employers or potential employers (excepting the armed forces) to discriminate on grounds of disability. Under this act, employers now must make 'reasonable adjustments' to the working environment or role of an employee with a disability, however, the act does not describe to what 'reasonable' is. In the 1998 Green Paper 'New Ambitions for our Country: A New Contract for Welfare' (Department of Social Security 1998) the Labour Government set out its position on both social security and employment, with the overall aim being to increase the proportion of people with disabilities in the workforce. However, further legislation was required and in 2004 the Disability Bill (Department of Justice 2004) was introduced, aimed at encouraging public employers to proactively target people with disabilities.

The various Government funded schemes and support programmes that can help people with disabilities to find or maintain work can be useful and relevant to those with PD but the lack of direction to these schemes leaves them underused by this group (Social Services Inspectorate 2001). Ideally the first point of contact for someone with PD should be the local Job Centre but is possibly not the most obvious choice for someone who is still in employment. The Job Centre will arrange an interview with the Disability Employment Adviser who can then signpost to available services and schemes. People with disabilities require a diverse range of strategies to enable them to stay in employment and what may be appropriate for one person may be of little use to another (Roulstone et al 2003).

Despite the legislation in place to protect people with disabilities, awareness of this legislation is low in both employees with PD and their employers (Banks and Lawrence 2006). The PDS found that only 23% of respondents were aware of the Disability Discrimination Act and 67% stated that they would welcome information and advice regarding employment (PDS 2002). Welfare and employment rights information is a big concern for people with PD. Having this information in the early stages of the condition and knowing where to go for support is particularly important (Morris 2003). However there is lack of support, information and advice for younger people with PD in regards to employment (Banks and Lawrence 2006).

People with PD seem reluctant to discuss their diagnosis with their employer. Only 58% of people with PD in Britain told their employer when they were diagnosed (PDS 2002)

and 22% of people with PD in Europe concealed their diagnosis from their employer (European Parkinson's Disease Association 2008). However generally this is without cause, as only 10% of younger people with PD said they had experienced discrimination from management at work since they disclosed their diagnosis and 18% reported experiencing negative attitudes from colleagues such as intolerance, ignorance or hostility (PDS 2002). Some people have experienced adjustments to help them stay employed which included a change in hours, change in job/duties, working from home offered, improved seating and equipment (PDS 2002). However this is not a common experience as only one in five people with PD had requested adjustments to be made to their employment (Banks and Lawrence 2006) People with disabilities have reported that the most effective assistance received is that which is considered to be informal from colleagues and managers but due to the informal nature of this assistance it can be withdrawn due to staff change or turnover (Roulstone et al 2003).

PD has been found to have a financial impact on individuals and their families partly due to loss of employment of both the individual with PD, and the loss of employment of family members when taking on the role of care-giver (PDS 2002, Bhatia and Gupta 2003, EPDA 2008). In Britain 73% of younger people with PD said that they had had to cope with increasing financial costs as a result of their condition, including prescriptions charges (PDS 2002). This is mirrored in other conditions (McCabe and Conner 2009), unsurprisingly people with MS are more financially secure when they are employed (Johnson 2004). People with conditions such as MS and PD are often at the peak of their career and earning potential when diagnosed (Fraser et al 2003), and if they leave work, the lost employment costs for people with MS has been found to amount to £4240 per year (McCrone et al 2008).

2.10 Vocational rehabilitation, occupational therapy and Parkinson's Disease

A detailed review of the literature focusing on interventions relating to employment for people who have PD was undertaken. The data bases searched were; Cinahl, Medline, AMED, Web of Science, Cochrane Library, Proquest and the National Library of Guidelines. The types of studies targeted included; randomised controlled trials, non randomised trials, quantitative research, systematic reviews, and qualitative studies. The search terms used were Parkinson's disease, employment, experience, occupational

therapy and vocational rehabilitation, the search strategy for a specific database can be found in Appendix N. Boolean Operators, truncation and wildcards were utilised to ensure that all relevant publications were captured. The search was limited to literature from 1990 to present day to allow a focus on contemporary text and only articles with an abstract written in English were considered. Reference lists from selected articles were cross checked with the results of the data base search for additional relevant titles. The PDS Information Officer and OT neurological special interest groups were consulted for advice regarding relevant text and accessing unpublished work. Of the articles found using this search strategy, most lacked the specificity required. Articles were found relating to OT and PD but with little consideration of employment, others were found which considered vocational rehabilitation for people with neurological conditions or chronic diseases, but not specific to PD. The search found a lack of literature regarding interventions to enable people with PD to maintain their employment. Articles that had 'employment' and 'PD' listed as key words were often found to be relating to the financial situation of people with PD and their care-givers who had given up work as a result of the condition, this theme has been discussed in the previous sub-chapter. Literature in this section of chapter was therefore included if it met the following subject criteria; vocational rehabilitation for people with chronic conditions, OT and vocational rehabilitation and neurological conditions, and PD and OT. Full text articles of the abstracts fulfilling these criteria were examined.

The term vocational rehabilitation is used to consider many processes in employment related intervention to help people who have disabilities or ill health to maintain their employment, re-enter the work-place, or retrain (COT 2008, Khan et al 2009). Much of the focus of current vocational rehabilitation in the UK is on a return to full time work from a state of unemployment or dependency on benefits (Runrill et al 2000), such as the Condition Management Programme which targets people in receipt of Employment and Support Allowance (previously Incapacity Benefit). Existing employment schemes focus on people with learning disabilities or mental health problems, with little attention given to people with physical disabilities (Social Services Inspectorate 2001). In the case of PD, as with other long term neurological conditions such as MS, the combination of two factors means that it is unsurprising that people with PD who are trying to retain their employment are unable to find support (Townsend 2008). This lack of vocational rehabilitation for people with neurological conditions is not just confined to the UK. In other European countries, the majority of people who indicated a need for

vocational rehabilitation had not received this service to the extent that they perceived necessary (Varekamp et al 2006, Ytterberg et al 2008).

An inspection of 'Welfare to Work for Disabled People' (DoH 2001) found that vocational rehabilitation services in the UK were separate, lacked multi-agency co-ordination and that little reference had been given to supporting employment in mainstream information. The Inspection discovered that health agencies paid little attention to employment as part of rehabilitation. The findings of this inspection were confirmed by a report published by the British Society of Rehabilitation Medicine (BSRM 2004) who agreed that gaps had arisen between employment and health agencies in regards to rehabilitation and that rehabilitation related to return to work has been taken over by employment services. The report stated that this resulted in difficulties for people who need support from specialist health services. The importance of medical professionals and vocational rehabilitation providers working closely together to promote employment for people with disabling conditions has been identified (Varekamp et al 2006).

Many studies have emphasised the need for health professionals to consider employment when providing specialist intervention for people with neurological conditions (Sweetland 2007, Khan et al 2009). Unfortunately studies have found that Allied Health Professions do not see employment as part of their remit when providing intervention to people with PD (Banks and Lawrence 2006). Health professionals demonstrate a lack of understanding or awareness regarding issues such as cognitive impairments and fatigue and do not advise on strategies that address these issues (Johnson 2004, Sweetland 2007). Research strongly indicates that health professionals with specialist knowledge of the neurological condition should provide vocational rehabilitation (Johnson 2004, Sweetland 2007, Khan et al 2009) as specific issues associated with neurological conditions are often missed by generic workers. Cognitive impairments in MS are now thought to contribute more to a withdrawal from employment than previously. Self reports of cognitive impairments have been found to be around 38% but with specific psychological testing are up to 70% (Johnson 2004). Issues such as these are unlikely to be considered by generic workers but appropriate intervention could be provided by health professionals with experience and knowledge of both vocational rehabilitation and the functional impact of neurological conditions. The COT published a Vocational Rehabilitation Strategy (2008) which describes their approach to vocational rehabilitation and the support for occupational therapists to

provide it. The strategy promotes the belief of the COT that people have the right to information and support to enable them to work. The early practice of OT was rooted in the philosophy that a return to occupation or employment following illness or disability is a major health indicator (Thurgood and Frank 2007). A current popular model of OT is the Canadian Model of Occupational Performance which identifies self-care, productivity and leisure as the three major performance areas within an individual's life (Townsend 2002). However, the experience of many people with PD when it comes to receiving OT is that the intervention is focused only on self-care. This practice is reflected in both the literature and in practice (Gaudet 2002). In the chapter regarding OT in a US PD text it makes no mention of intervention in relation to employment or leisure (Gillen 2000) and the chapter focuses only on self-care activities. This is fairly typical of the experience of younger people with PD. A survey of current OT practice in PD in the UK found that although the occupational therapists in the study targeted a wide variety of goals, they mainly focused on physical self-care and functional abilities such as transfers (17%), mobility (17%), washing and dressing (14%), eating and drinking (9%) and not wider social and psychological aspects of occupation (Deane et al 2003b). In a study of 168 clients using community OT services in Norway, it was found that only 17% of these clients participated in employment activities and that 94% of participants reported difficulty with education, work and employment, however the participants in this were from a mixed caseload and only 24% had neurological conditions including PD (Aas 2007). A Delphi survey of best practice in OT in the UK for PD found a consensus amongst therapists of between 99 and 100% that in an ideal world the specific expertise of occupational therapists would be focused on improving or maintaining function in work and leisure. Although this study does not consider a specific intervention, there was consensus around many of the areas of function that would support the maintenance of work activities such as energy levels (to combat fatigue), decreasing the impact of social stigma, and problem solving techniques (Deane et al 2003c). Occupational therapists can enable someone to adapt their performance of activities, which could include employment, when illness has affected their usual way of performing activities, this in turn can lead to long term improvements in participation and QOL (Lorenzen 2008). Occupational therapists have been identified as holding the skills needed to provide vocational rehabilitation for people with similar progressive conditions such as Multiple Sclerosis (MS) (Sweetland 2007) and a recent study has

reported that OT intervention can improve work-related outcomes in people with rheumatoid arthritis when maintaining people at work (Macedo et al 2009).

So although referral to OT services could provide assistance in the maintenance of employment, both the access to OT services and the service provided in relation to employment is limited. Despite OT for people with PD being recommended by many studies, guidelines and researchers (NIHCE 2006, Rajput and Rajput 2006, Ferraz and Borges 2002, MacMahon 2000), surveys have shown that although there has been an increase during recent years for access to OT intervention it still remains heavily rationed and referrals are 'sub-optimal' (Nijkrake et al 2009). In the 1980s and 1990s only 13 – 25% of people with PD had access to OT (Oxtoby 1982, Mutch et al 1986, Clarke et al 1995, Yarrow 1999). In 2008 this had only risen to 34% with people more likely to receive intervention from a Speech and Language Therapist (SLT) or physiotherapist (PDS 2008). The lack of provision of OT by the NHS may be partly explained by a lack of evidence of the efficacy of OT, as documented by previous and recent Cochrane and systematic reviews (Deane et al 2001, Fuchs 2003, Gage and Story 2004, Dixon et al 2007). One of the difficulties acknowledged by these reviews is that there is no consensus on what constitutes 'standard' OT for this client group (Deane et al 2001) or how to evaluate OT intervention although 3 tools have been recommended for an OT evaluation of individuals with PD which are the Canadian Occupational Performance Measure, the Unified Parkinson's Disease Rating Scale and the Parkinson's Disease Questionnaire (Gaudet 2002). However a recent pilot of an Randomised Controlled Trial of OT in PD sought to establish an optimum OT intervention and then to carry out a national RCT (Clarke et al 2009) which will provide evidence in relation to the efficacy of OT. Those using a 'standard' intervention however should be mindful of ensuring that intervention should be individual to each person with this condition and consider not only their age, stage of the condition and cognitive impairment but how the condition interferes with their social and occupational functioning (Jankovic 2000). In addition reports have identified that occupational therapists working with people who have PD should have specific expertise (Nijkrake et al 2009, PDS 2008). Recently, the College of Occupational Therapists have commissioned the development of guidelines for OT in PD which should be available early in 2010.

There is a lack of evidence regarding vocational rehabilitation and PD, however, there is a body of literature concerning vocational rehabilitation and MS or other chronic conditions. A Dutch study (Varekamp et al 2006) considered the effectiveness of

vocational rehabilitation interventions for people with chronic conditions. PD was not identified in this group of conditions which included diabetes, hearing disorders, chronic kidney failure arthritis and MS. This article examined the literature relating to vocational rehabilitation interventions for people with these conditions. However, the authors only considered articles that described an intervention which used an empowerment perspective. They define an empowerment perspective as,

"...offering knowledge and skills to clients which enable them to adopt an active attitude in defining and solving problems" (Varekamp et al 2006). However, the authors acknowledge that job retention is not just the responsibility of the employee alone, employers and national policies also contribute. They authors selected nine studies, which met their criteria, published between 1991 and 2003. They reported that due to the heterogeneity of the selected studies and the limited number of studies, a meta-analysis was impossible. Although this systematic review lacked analysis, its description of the components of a vocational rehabilitation programmes was constructive. The authors emphasise the need for a comprehensive conceptual model based on a social perspective which understands work-related problems and work disability, and stress the importance of a focus on self-efficacy and self-confidence, and indicate that programmes based on education alone are insufficient. A subsequent article by the same author (Varekamp et al 2008) describes a seven-session group training programme combined with three individual counselling sessions for Dutch employees. This intervention programme was targeted at people with chronic physical conditions including musculo-skeletal conditions, arthritis, endocrinological diseases and neurological conditions such as PD. The philosophy of the programme includes; empowerment, personal and environmental factors, communication and self-efficacy. Although this article presents a detailed description of an intervention programme and a plan of evaluation for that programme, it lacks rigor in its description of how the intervention was developed. The reasoning underlying the number sessions and timing of the sessions, and why a group, rather than an individual programme was developed is not explained other than identifying that group meetings are seen as being a method for enhancing self-efficacy. The study was funded by the Dutch ministry of Social Affairs and Employment and an occupational health agency indicating a positive move by the Dutch government to encourage people with chronic physical conditions to retain their employment. The evaluation of this intervention has not yet been published so its efficacy is unknown.

An examination of the remaining literature produced a catalogue of attributes that should be considered in a vocational rehabilitation programme for people with neurological conditions. Traditionally vocational rehabilitation is concerned with helping people regain work however the focus in this study concerns assisting people to retain their employment and therefore factors than can facilitate this process have been drawn from the literature.

In a commissioned review of the health of Britain's working age population it was stated that what would help people remain in or quickly return to work following the onset of a chronic illness was intervention provided early following the development of a health condition (Black 2008) which should be delivered on an individual basis (Sweetland 2007), rather than the group basis described in the Varekamp (2008) study. The provision of intervention early in the course of the condition could assist people to address potential difficulties such as discrimination before situations deteriorate (Unger 2004).

The attitude of employers has been found to be a significant factor in maintaining employment. Employers with a positive attitude to making adjustments in the workplace, allowing employees a flexible work schedule that includes working from home and having supportive colleagues can assist people with MS to maintain their employment (Unger 2004). People with PD who felt that their employer had enabled adjustments to be made and had stayed in work for longer (5.4 years) than people who did not believe that their employer had been supportive (3.2years) (Banks and Lawrence 2006).

Research indicates that a comprehensive conceptual model is required to understand work related rehabilitation. The model should focus on providing interventions to change behaviour (individual) and modify the environmental (external) (Varekamp et al 2006) and the intervention should be specific to employment and targeted (Macedo et al 2009). Behaviour modification interventions include self advocacy training, information about rights, and problem solving procedures to tackle issues (Unger 2004). Programmes need to include interventions that support emotional self management (Jackson and Kelsey 1999, Fraser et al 2003) such as reducing stress and anxiety (Rumrill et al 2004b, Banks and Lawrence 2006), the promotion of self efficacy and confidence (Varekamp et al 2006) and to help individuals disclose their condition and adapt and adjust to complex issues (Sweetland 2007). There is a need for the targeted

provision of high quality information, advice and education regarding disability legislation and discrimination (Jackson and Kelsey 1999, Banks and Lawrence 2006, Varekamp et al 2006, Sweetland 2007). Flexible working patterns such as working from home can help individuals to cope with the impact of symptoms such as fatigue (Fraser et al 2003 Black 2008). Changing their work role, understanding the impact of their symptoms on their performance at work and adaptation of their working environment can assist people with neurological conditions to maintain their employment (Jackson and Kelsey 1999, Sweetland 2007).

The positive aspects of being in employment may not be recognised or appreciated until those opportunities are relinquished, (Yerxa 1998) so supporting a withdrawal from work, at an appropriate time is just as important and valuable as supporting maintenance of work, as continued employment may be detrimental to other aspects of the individual's life such as family and social activities (Khan et al 2009). Meaningful occupation usually takes the form of employment in most working age adults or leisure activities if employment has been lost, as engaging in meaningful leisure activities can prevent occupational deprivation in an individual with a neurological condition (Fenech 2008). However it has been found that people with neurological conditions require assistance to continue with activities that can provide social support (McCabe and O'Conner 2009), therefore any intervention must include a plan of withdrawal that promotes engagement with 'replacement' activities.

2.11 Conclusion to Review of Literature

This chapter has assisted in elucidating the research aims established in the previous chapter and identifying both the current knowledge in this area, and the gaps in that knowledge. The literature highlighted that there are wide ranging motor and non-motor symptoms of PD that can impact on an individual's ability to maintain employment. Although vocational intervention typically focuses on motor symptoms, the literature has identified that the non-motor symptoms, perception of condition and assumed control of condition have a greater effect on QOL in PD and other neurological conditions. QOL is positively associated with employment, as employment can promote self-esteem, identity, and social interaction. Many people with PD do not maintain their employment and may have a long time to live with the consequences of unemployment. The repercussions of early retirement can be wide ranging and require considerable

psychosocial adjustments. Studies have indicated that depression may be the first symptom of PD and may mean that people with PD are unable to engage coping mechanisms to maintain their employment or indeed that withdrawal from employment may contribute to depression.

The meaning of employment for working age adults with disabilities was explored in the literature, however the literature did not reveal a specific account of the employment experience of younger people with PD. Maintaining employment can improve QOL by providing a meaningful and social activity for adults to engage in and could have a positive impact on the social 'symptoms' of PD with a subsequent positive effect on maintaining positive family relationships. If a person is able to adapt either their performance or their environment to maintain their employment then this can promote a sense of empowerment and self-efficacy regarding their condition which in turn again can improve QOL.

Younger people with PD are reluctant to become involved in education or support groups and these groups are often lacking in the provision of information relevant to their age group, such as employment advice. To further exacerbate the problem, people with PD usually do not receive appropriate or effective intervention to assist them to maintain employment through standard statutory routes. Occupational therapists are ideally skilled to deliver intervention to maintain employment but currently the focus of their intervention is on self-care activities, even though they feel they should be providing intervention in this area. Intervention to maintain employment should be provided early in the onset of the condition, targeted and delivered by professionals with specialist knowledge of PD and the skills to promote adaptation of the individual's performance and their environment. Overall the literature indicates that intervention needs to be provided to enable younger people with PD to maintain their employment, but, is currently unavailable. The literature will be returned to in Chapter Five, when it will be examined alongside the data and utilised to support the seven stage intervention presented in that chapter.

The next chapter will identify and describe the methodological design framework that will enable further exploration of the research aims.

3 Methodological Design Framework

3.1 Introduction

This chapter aims to establish both the theoretical framework that guides the research, and, the methodological approach to the collection and analysis of data, to enable the exploration of the research aims. The aims of this research were:

1) To understand the employment experience and trajectory of younger people with PD

2) To model an intervention to assist people with PD to maintain employment.

To achieve these aims, the following objectives were set:

i) Explore the meaning of occupation for younger people with PD

ii) Identify the aspects of work that may be beneficial to someone with PD

iii) Understand the strategies used for maintaining work by people with PD

iv) Appreciate the decision making process utilized by younger people with PD when choosing to remain in or leave work.

The previous chapter identified that the experience of employment in PD has not previously been explored to the extent that a definitive conceptual model has been identified. Therefore it would be impossible to create an enquiry that accepts a previously identified reality. In this case to create a potentially useful clinical intervention, the reality of the experience on which the intervention is to be applied (PD and employment) must first be identified. This project will therefore generate theory rather than verify it. In this chapter, the philosophical assumptions that underpin the research will be established followed by an introduction of the main influencing drivers in this research. Finally the methodological approach will be explored which will include a description of the validity procedures. The following chapter (4) will describe the data collection process and the data analysis, and therefore the operational use of methods will not be included in this chapter.

3.2 Philosophical assumptions

An approach to this project was required which would sit comfortably within an OT framework and as such would appreciate client culture, would be client centred and would question policy, power issues and social inequalities. A participatory approach was required to facilitate the drive towards implementing change fundamental to this project. All these elements were required in a flexible design that was not dictated by a specific set of data collection tools, rather, allowing the tools to be indicated by the need for adequate information, efficiency of collection, and the competency of the researcher. Following consultation and investigation of literature, social constructionism was selected as the methodology framework required to guide this investigation.

A view shared between Social Constructionist and Action Researchers is the belief that the aim of the research should be in facilitating change or 'change intervention'. In addition the research does not seek to reveal the 'truth' but to create a useful and pragmatic outcome (Burr 1995). Social Contructionism demonstrates an affinity with Ethnography as it seeks to explore and understand how individuals or 'social actors' come to intersubjectively share understanding, meaning and knowledge of social constructs and specific life circumstances (Denzin and Lincoln 1998, Schwandt 1997). This methodology is particularly relevant to this study as it aims to gather a collective understanding of employment and examine how this knowledge was constructed in relation to social processes.

A clear ontology and epistemology needs to be established at this stage which will clarify the philosophical assumptions and link these with the methodology. The ontology that underpins this project is based on the research tradition of interpretivism (Figure 2, number 4), the origins of which lie in sociology and it regards social reality as the interpretations, expectations and shared understandings of actions and situations within the social world (Blaikie 1991, Ritchie and Lewis 2003). Social reality is not thought to be concrete but is formed through socially constructed meanings and regulated by normative expectations (Ritchie and Lewis 2003).

The epistemology of this interpretivist framework derives knowledge from everyday meanings and interpretations and this knowledge is gained by *"... entering the everyday social world in order to grasp the socially constructed meanings..."* (Blaikie 1991 p121)

The phenomena to be studied are 'interactive' and the researcher is not approaching this from an objective viewpoint but acknowledges that in an interpretivist framework the researcher and the social world impact on each other. In addition within this framework research is undertaken via a shared investigation (researchers and participants) of meanings and explanations and these findings can be 'value mediated' by the researcher or mediation can be negotiated through the researcher and participants (Ritchie and Lewis 2003). This negotiation and joint approach with the research participants is a fundamental part of this study and will be further explored later in the chapter, however it is acknowledged that due to the length of time working in this area there may be deeply ingrained assumptions and preconceptions held by the researcher that may create a weighting or bias when results are considered. It is part of the research process to ensure that any assumptions or pre-conceptions are made as transparent as possible,

"The task of researchers therefore becomes to acknowledge and even to work with their own intrinsic involvement in the research process and the part that this plays in the results that are produced." (Burr 1995 p160)

A visual representation of how these factors interface is given in Figure 2. This representation, and the following chapters will describe how the idea for this investigation is initiated from a clinical question (Figure 2, number 1) and uses the methodological process (Figure 2, number 2) to develop a 'macro' idea (Figure 2, number 3). Applying a sequential transformative strategy (Figure 2, number 5) the experiences of the research participants will be explored utilising a range of data collection methods (Figure 2, number 4) and will simultaneously be refined by the analysis procedures (Figure 2, number 6). The result of this process will be a 'micro' outcome (Figure 2, number 7), a mass observation taken through an individual lens. The outcome will then be validated with clinicians (Figure 2, number 9) and then tested in clinical practice (Figure 2, number 8) before being used in the researcher's clinical practice (Figure 2, number 10).

Figure 2 – Methodological Design Framework

1) Clinical Question (Practitioner research)

2) Interpretative methodology

3) MACRO

4) METHODS

Questionnaire → Focus Groups → Stories

Sequential Validation with Participants

5) STRATEGY

Sequential Transformative Strategy

Narrative Influence

6) ANALYSIS

Descriptive Statistics → Thematic Analysis → Production of Intervention

Social Constructs

7) MICRO

8) Validation in Practice

9) Validation with Clinicians

10) Clinical answer transferred directly into practice

3.3 Practitioner Research

The philosophical assumption has established that the researcher is one of the central elements in the research process in this study. This section will further explore the influence of the researcher as a practitioner in the research process.

The methodological framework selected for this project needed to encompass the researcher's professional background of OT and as such, a social rather than a medical model was required that reflected the ethos and values of the profession and will would value the influence that people with PD have on the research process. This study was conceived in practice and a clinical question was developed from the researcher's practice area which represents one of the major influencing factors in the development of the methodology. So, not only did the philosophical framework have to be sympathetic to the researcher's professional beliefs, but also the methodological process, the process itself being as important as the outcome. In addition, as the researcher wanted to change current practice, a methodology was required to bring together a contribution both to knowledge and practice (Robson 2002). The methodological framework is therefore required to produce a clinical answer that could be applied to practice. The selected methodology has to fulfil many needs in this study however, these needs can be viewed as constructive contributors to the inquiry. Two features of this particular investigation that are considered by researchers to characterise the development of successful research are firstly having an established and accessible network of contacts and colleagues and secondly the investigation being initiated by a problem arising 'in the field' and having a 'real world value' in that it creates useful ideas (Campbell et al., 1982). The first feature acknowledges the contacts that the researcher has established as being essential to an investigation of this type. In this case 'contacts' refer to not only colleagues within the field but the involvement of people with PD themselves. This amounts to a wide network of potential contributors and stakeholders in the research. The network itself establishes the context of this study. Having knowledge of both the statutory and non-statutory systems in which the person with PD may try to get help regarding difficulties with their employment and the lack of assistance available within these systems prompted the need for this investigation. The researcher had

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worked within the field of PD for many years and had established a nationwide network of contacts within health, employment, social services and the PDS to support her clinical work and these contacts were vital to enabling access to the participants in the study.

The second feature highlights the need for practitioner research in that the research questions should arise from the researcher's clinical practice and then contribute an 'answer' within that field. The need to explore the influence that PD has on employment and to develop an intervention to guide an approach to these difficulties was identified through regular exposure to the problems brought by individuals with PD to the researcher's out-patient clinic. This need was not being addressed and was having a detrimental impact on the QOL and symptom management of people with PD. This tacit knowledge gained from in-depth knowledge of the subject area directed the development of the research question. This study is therefore firmly rooted in practitioner research. The researcher's professional background and clinical experience informed the whole process. The development of the question, through to the design of the research was governed by *'therapeutic imperatives'* (Reed and Procter 1995 p30) and the need to improve the researcher's clinical practice and directly and positively influence the management of PD. Table 1 illustrates how the researcher in this study has used an 'insider' approach to the whole research process in this study, from establishing aims and role, negotiating access, designing and planning, analysing the data and disseminating the results. The polarisation of approaches to research has been described with objective, 'outsider', depersonalised research at one end of the continuum, typically undertaken by researchers with no professional experience. At the opposite end of this spectrum is research that is 'insider', undertaken by practitioners into their own area of practice, and as such is personalised, informed by experience and, influenced by the researcher (Reed and Procter 1995).

Table 1 - Illustrating the 'Insider' position of the researcher

'INSIDER'	APPROACH IN THIS STUDY
AIMS The primary aim of nursing research is usually to solve a critical problem, thereby contributing to the body of nursing knowledge	**AIMS** The research will contribute to the body of knowledge regarding people with PD's experience of employment and provide an intervention in an area of unmet need
ACCESS Their choice of research setting is limited but their contact is deep	**ACCESS** Access negotiated with the PDS to allow access to a range of settings to capture the experiences of people with PD. Existing roles and networks utilised local contacts
NEGOTIATION OF ROLE The nurse researcher is a *member* of the world being researched. They may have multiple roles, some of which are permanent	**NEGOTIATION OF ROLE** Existing member of the world being researched. Temporary role as a researcher and permanent role as a practitioner.
DESIGN AND PLANNING Informed by insider knowledge and frequently governed by therapeutic imperatives	**DESIGN AND PLANNING** Governed by the imperative to provide a therapeutic answer to a clinical question.
ANALYSIS Shares taken-for-granted assumptions the significance of which may not be recognized	**ANALYSIS** Depth of experience from working with patients in practice progressed naturally to involving patients in the analysis procedure.
DISSEMINATION & COMMITMENT To colleagues, professional and academic communities. Concerned about the way in which the research is used both locally and professionally	**DISSEMINATION & COMMITMENT** Dissemination to the clinical community promoting use of the research and changing practice. Dissemination of the results to people with PD and the PDS

Table adapted from Reed and Procter 1995 p30 - the column on the left is taken directly from Reed and Procter (1995), the column on the right interprets the 'insider' position of the researcher in this study.

3.4 Consumer Involvement

Government policy and NHS Research Governance calls for the involvement of service users and the public in health and social research (DoH 1998, Goodacre et al 1999, DoH 2000a, DoH 2000b, DoH 2005b). A survey commissioned by Consumers in NHS Research found that consumer involvement in trials made trials more user-friendly and improved the relevance of both the questions asked in the research and the results obtained (Hanley et al 2001). The term 'consumer' is used to describe service users, carers and others affected by a condition, illness or disability (DoH 2005) and 'consumer involvement' has been described as doing research with consumers rather than to, about, or for consumers (Royale et al 2001).

The relationship between the researcher, people with PD and the research topic are integrated within this investigation. The philosophical framework has indicated that within the research process the people with PD are not simply viewed as the source of data, but are integral to the process. In this study the people with PD are identified as users of the results of the research in addition to being the subjects of the research. The study design was co-produced with people with PD who were participants in its design (Arnstein 1969). An opportunity for participation occurs at each stage of the research process and is considered, alongside Practitioner Research to be a major influencing factor of this investigation. Using people, who have personal experience in the area of focus, to guide the investigation can address many ethical and methodological factors. The traditional method of research enables users to get involved during one key stage i.e. data collection, and they can then have access to the results during the dissemination stage which results in non-participation or 'tokenism' (Arnstien 1969), however in a consumer involvement methodology they are involved in each stage. A flexible research design has been constructed to include a strong consumer consultation focus which is illustrated in Figure 3. This focus has been described as 'participative' and that as the results will be actionable and generalisable coming from context bound knowledge, there is a high likelihood that the participants will use the results (Reason and Rowan 1981), underpinning the clinical contribution that is the primary motivation for this study. Within a consumer involvement approach, the roles of the researcher and participants becomes that of colleagues contributing towards shared learning, an approach which mirrors the clinical practice of OT and, in particular, the collaborative practice that the researcher has developed when working with people who have PD.

Involvement of the research population not only as informants but as co-directors of the research was essential and social constructionism provides the framework for this joint responsibility to emerge. The involvement of consumers, as with the influence of the researcher being a practitioner will be manifest in each part of this study. The process and method of user involvement in this study will be detailed in the next chapter and further exploration of the utilisation of the contribution of users is discussed when describing the validation of the research.

3.5   Research Design

When selecting a methodological approach for this study there were several factors that required consideration:

- The subject matter of the study was complex and a single measure of meaning was not immediately apparent.

- A methodological approach was required that would allow some development during interaction with the study informants but also include some pre-determined data collection methods.

- The methodology must be sympathetic to the philosophical approach and reflect a consistent ontology and epistemology.

- The approach must fit comfortably within the professional beliefs, skills and resources of the researcher.

All of these factors pointed to a design that was flexible and contained a variety of data collection methods. Both qualitative and quantitative methods were required for data collection in this investigation. Flexible Design (Robson 2002) can include methods typically labelled as quantitative and also those historically labelled as qualitative, in effect, a multi-method design which would be appropriate for this investigation.

Multi-method research has developed in popularity in social science and practitioner research as a balance between the rigidity of selecting a single philosophical position and the pragmatism of choosing an appropriate approach. Two approaches to multi-methodology have been proposed in the literature. Firstly using different methods from the same paradigm and secondly the mixing of different paradigms within a single research design, however the latter approach may lead to "a lack of analytical

clarity" (Ritchie and Lewis 2003 p17). The way forward for this study is therefore to look for a consistent ontology and epistemology whilst utilising the pragmatism of appropriate data collection methods. Research literature indicates a move away from an inquiry being either quantitative or qualitative with its associated specific methods, to the emphasis now being on the 'approach', the elements and strategies that inform the inquiry or the epistemology and theoretical stance (Blaikie 1991, Creswell 2003, Ritchie and Lewis 2003). In addition, problems can be created if the research is not theoretically or conceptually focused and methods based on different ontological and epistemological assumptions are used (Jick 1979).

The epistemological stance in this study is to seek an understanding through an interpretivist, constructivist stance, however, in the study, quantitative data was gathered which would indicate positivist tendencies, but this data was gathered, analysed and utilised in order to set a context for understanding rather than an end point in itself. This indicates that the methods in this study are compatible with the identified ontological and epistemological stance (Creswell 2003).

The term Multi-Method has largely replaced both the title and the concept of triangulation (although these terms are often used interchangeably) and was first initiated by Campbell and Fiske in 1959 then developed and defined by Denzin in 1978 (in Jick 1979 and Blaikie 1991). At first the term was a metaphor taken from navigation and surveying gaining multiple viewpoints or angles to plot a precise point or location. This translated into social research by as 'methodological triangulation' the use of multiple methods or 'between-methods' triangulation to explore a social phenomena and ensuring validity.

"…triangulation is supposed to support a finding by showing that independent measures of it agree with it or, at least, don't contradict it" (Miles and Huberman, 1984 p 235)

More recently however, there has been a move away from multi-methods simply been viewed as a way of solving the deficiencies of a single data collection method and is seen as a technique in which a contextual portrayal of the social world is captured from this 'better' form of evidence and meaningful propositions are constructed (Mathison 1988, Creswell 2003). In addition, multi-method research is acknowledged as 'host' for the development of inventive, creative and ingenious

methods to collect data and demands insightful interpretation of results (Jick 1979, Creswell 2003) which relates well to the flexibility required in Practitioner Research.

An interesting outcome of the debate around the use of triangulation is that it allows quantitative methods for data collection to make a contribution and to influence previously 'pure' fieldwork methodologies (Jick 1979). This is a justification for approaching a qualitative study in a systematic way and enabling quantitative methods to be used to frame qualitative methods in order to elicit the best data. This identifies the rationale for the use of multi-methods in this study, not just a need for validation in a positivist way via multiple perspectives, but a search for a deeper understanding of the topic to satisfy the interpretivist need for meaning and reluctance to accept accounts at face value. In multi-method research this need is met by enabling explanations of social phenomena to be constructed and extrapolating the 'hidden meaning' (Mathison 1988).

Acknowledging that multi-methods (Fig.2, no.10) was the most appropriate methodological approach for this investigation a direction for the way in which it could be successfully used in this investigation was sought. Strategies of enquiry employed by mixed methods research collect data either simultaneously or sequentially and these designs can be described as either sequential, concurrent or transformative (Creswell 2003) however the strategy employed to guide the use of multi-methods in this study is sequential transformative (Fig.2, no.7) (Creswell 2003). Although the data collection methods used in this study are detailed in the next chapter, an indication of the methods used is given now to illustrate how they have been guided by the chosen methodological strategy. An assumption in a sequential transformative strategy is that the collection of diverse types of data will provide a better understanding of the research problem. This study will begin with a questionnaire given to a national sample which will generalise the results to the population, and then a second phase to collect detailed views from participants via focus groups then finally individual stories focussing on key aspects of the inquiry identified in the previous two phases. This sequence follows an example of sequential transformative enquiry detailed in Creswell (2003), and the priority in this investigation is given to the qualitative, or second phase.

The qualitative data gathered in this investigation is used to describe the results gathered in the initial questionnaire stage (Fig. 3, phase one). However, when first planned the emphasis was placed on the quantitative data collection (Fig. 3, phase

one) with the intention that the qualitative data (Fig. 3, phase two) would explain the quantitative. However, it was during the preliminary analysis of phase two that it became apparent a further stage of data collection was required (Fig. 3, phase three). This flexibility of the use of methods is key to the sequential transformative strategy. Reflecting the impetus of this investigation the sequential transformative strategy utilises a theoretical perspective or conceptual framework to guide the study and it is this conceptual framework that is of primary importance and is not a study driven simply by method alone. The use of distinct phases in this strategy is considered to be a major strength as it facilitates the *"implementation, description, and sharing of results…"* (Creswell 2003 p217) and provides *'a rationale for mixing'* (Creswell 2003 p19). This rationale is carefully considered and described during the next chapters as first the data collection methods are detailed with reference given to influence of each phase on the subsequent one and then the results are discussed with priority given not simply to the presentation of the analysis, but how these results can be shared in practice.

To date, there has been little written on this approach to guide the researcher (Creswell 2003), and warnings are given of the time required to complete the data collection phases. The research process in practitioner research and particularly in social constructionism, is a fundamental part of learning and the aim of the research is not simply the delivery of an outcome but has an explicit purpose of change intervention and the attainment of a useful and pragmatic goal (Burr 1995) which fulfils the aim of this investigation.

3.6 Validation

A mention of validation is made here in relation to the chosen methodological approach, in addition the subject of validation will also be explored in relation to the data collection methods utilised in this investigation in Chapter 4.

The research questions constructed for this project were developed from personal theory, previous research and real world observations from the researcher's clinical experience. Although they were validated with the research population the impact that the researcher's perception of the situation both in terms of developing the research questions and being part of the data collection will need to be acknowledged by separating and then comparing the researcher's meaning and the participants'

meaning. In particular, the participants' own account of their experiences must be validated by the participants' themselves, rather than by the researcher giving their own interpretation (Burr 1995). This validation is known as 'reflexivity' by social constructivists and sits comfortably within the framework required for this investigation as the emphasis lies with clarifying the respondents' views and values of a situation rather than challenging them (Denzin and Lincoln 2003).

Multi-method research is often advocated in social research as a way of trying to overcome issues of bias and validity, in that the combination of methods can overcome deficiencies in a single method (Mathison1988). However, the case for multi-methods is supported as a way of achieving a range or depth of understanding not as a way to increase validity and decrease bias. In the interpretative perspective, multi-methods can be used to challenge doubts regarding the validity of the interpretation of the data due to the understanding of an inequity of power in the individuals who provide those accounts (Blaikie 1991). However Mathison (1988) proposed an alternative conceptualisation of validity in triangulation, three outcomes that might result from this approach are convergence, inconsistency and contradiction.

In this investigation, multi-methods will be utilised for achieving a data set from which meaningful propositions can be drawn or convergence sought rather than for absolute validity, as the importance of this investigation is in making sense of the data gathered. Convergent validation is sought in this investigation, which is defined as the agreement of data from different methods or sources (Mathison 1988).

Although validation in this investigation will be a consistent element throughout the data collection process and will be described in detail in Chapter 4, specific validation of this research will be largely determined in two stages, firstly with a sequential validation of results with a steering group (Fig. 2, no.6) which sits comfortably within the research design framework as validity in interpretivism is based on convention and the willingness of the participants to find an acceptable account of their world (Blaikie 1991).

Then secondly by the development of an intervention framework (Fig. 2, no.6) as the fundamental requirement of practitioner research is to have an impact on the researcher's clinical practice. This is gained either through an understanding and explanation of the phenomena (Mathison 1988) and/or as is the intention in this

investigation, the creation of an intervention, and through the sharing of this intervention with other clinicians (Fig. 2, no.9), as the implementation and sharing of the results underpins the purpose of this study.

3.7 Conclusion to Methodological Design Framework Chapter

This chapter has established and justified the methodological design framework that will be used to guide the study in achieving its aims. An interpretative methodology directed by a clinical question and influenced by the professional beliefs and practices of the researcher led to a sequential transformative research design being selected for this investigation. Following the warnings issued by many writers when disputing the use or usefulness of multi-methods in social research, in this investigation a consistent epistemology is established and convergence identified through different sources of data and utilising a variety of media to enable participants to relay their story within an interpretative ontology. This enabled the collection of data ranging from the social and cultural concepts of experiences or a 'macro' concept (general opinions) to personal or 'micro' concept (individual stories) or the meaning or impact of those experiences on the individual. The research design in this investigation focuses on the realities of the lives of the people involved in the research and in parallel to the OT process, one of the most important elements of the project does not necessarily lie in a single data collection tool but rather the process and in particular the involvement of users in the research process.

Sequential transformative design is a flexible, multi-method design with the conceptual framework being of primary importance rather than being driven by a single data collection method, allowing changes and developments to be made during an exciting and emerging research process.

Figure 3 – Illustration of data collection phases, consumer consultation, validation & implementation of results

4 Methods

4.1 Introduction

The previous chapter described the methodological design framework for this study. In this chapter the sequential transformative strategy approach to a mixed methods design used to collect the data in order to further explore the research aims will be presented. The methods and tools used to collect the data and the approach to analysis will be described in this chapter. The results of that analysis can be found in the following chapter.

The methodological process is divided into four phases (Fig. 3). The first phase includes the establishment of a steering group, consisting mainly of younger people with PD, the ethical approval process and the pilot of a questionnaire. The second phase describes the distribution of the questionnaire and the sources and descriptions of the questionnaire respondents. Phase three discusses the rationale for the selection of focus groups as a data collection method and describes the planning and implementation of the groups. In the fourth phase of data collection, a contextual portrayal of the participants' experience of employment was sought using a web-based tool created using the themes gathered from the first three phases of data collection and through consultation with the steering group.

The phases in this data collection process were developed within a reflective approach. Each data collection method was informed through initial analysis of the data collected previously, and underpinned through validation with the steering group and interaction with the PDS. This approach allowed a 'rationale for mixing' (Creswell 2003) to be developed enabling the data collected to be integrated at different stages of the inquiry.

The use of more than one type of data collection method was employed as the intention was for the data to be developed into theoretical constructs. Multi-methods of data collection give the opportunity for more data to be collected to confirm or contradict the emerging theory. The aim for this type of data collection is to refine the emerging themes rather than continue to increase the size of the sample (Denzin and Lincoln 2003). The main data collection methods chosen for this project were; a questionnaire to look at frequency and distribution of characteristics, attitudes and beliefs followed by focus groups that used ethnographic questioning, then a final data collection phase

involved the development of a case study format by individuals with PD and the subsequent donation of personal experiences cited in that format.

Indefinite triangulation (Cicourels 1973) as a means of validity was used in the study. The data collection methods and the results impact on each other and guide the development of subsequent tools. Clinical experience, relevant literature and consultation with the steering group were used to compile the questionnaire. The results of the questionnaire were used to formulate the focus group schedule. The data from both of these sources were presented to the Steering Group who then validated these results in relation to their own experiences. This resulted in the production of a third data collection tool, the results of which created a contextual portrayal of the investigated experience. Utilising the described strategies, convergent validation of the results was achieved.

Although both quantitative and qualitative data analysis are used, the data sets will not be considered in isolation, rather, the quantitative data will enable a thematic analysis framework to be constructed to test out the content of the qualitative data, and the process of coding and categorising will further enable questions to emerge. Such an approach to data collection and analysis has been acknowledged as being unwieldy, lacking in direction and is time consuming (Marshall and Rossman 1995). However, in this multi-methods study, analysis is an important element in cementing the interpretation of the results (Jick 1979) and both the data analysis and the methodological approach have served to provide the consistency in this multi-methods study.

In this chapter the approach to analysis of each of the data collection methods will be proposed and throughout every phase, reference will be made to the methodological design framework described in the previous chapter.

4.2   Phase One

4.2.1   *Funding application and development of a Steering Group*

The initial research question was developed in collaboration with a group of younger people with PD. They were a newly established support group for younger people with PD situated in northern England. They were consulted as to the importance of the research topic in their lives. The group felt that maintaining employment was an area of

difficulty that was under-recognised and therefore warranted further investigation, particularly if an intervention was developed as an outcome. Following validation of the research question with this group it was submitted to the PDS for funding through a grant application procedure. The application was successful and a steering group was formed. The steering group consisted of the members of the support group and an Area Officer of the PDS. They were joined by a brother of one of the members and the researcher's PhD project supervisor. The steering group met quarterly and any additional information was circulated via e-mail. In addition to this group, regular discussions took place with the PDS Community Support Officer who was able to give advice and suggestions regarding access to the PD population.

4.2.2   *Development of a questionnaire*

Following an examination of the literature it was discovered that little was known about the specific impact of PD on employment. The available information was generic to a range of conditions and although this project required data from in-depth experiences, it was difficult to gather this information at an initial stage. This first stage of data collection in the chosen sequential strategy was required to 'set the scene', and identify and describe the distribution of contributing factors and characteristics (Marshall and Rossman 1995). This would enable the socially constructed meanings surrounding the experience of employment for people with PD to be established. The collection of this type of data could be efficiently achieved via a postal questionnaire to enable responses to be drawn from a large number of people across a wide geographical area.

Entering into this endeavour was not undertaken lightly. Research design literature is full of warnings of the potential pit falls of questionnaire design, in terms of time to create, question types, ambiguity, bias and low response rate (Drummond 1996, Oppenheim 1992, Youngman 1986, Marshall and Rossman 1985). Each of these issues was carefully considered, advice taken from the literature and versions cross-checked with the steering group.

Initially, a fully structured questionnaire was considered due to the difficulties many people with PD encounter when writing such as micrographia, dyskinesia and tremor. A fully structured questionnaire would allow multi-choice responses indicated by ticking a box, thus reducing the amount of writing required by the respondent. However, the literature did not reveal the type of information to enable all responses to be pre-

defined, which is the basis of a fully structured questionnaire. Following consultation with the steering group it was decided to take a semi-structured approach to the questionnaire, in order to avoid pre-defining responses, to allow a greater depth and breadth of response and to maximise the response rate.

To identify the themes required, a review of relevant literature was undertaken including web-sites, PDS publications, Department of Health, Department of Work and Pensions and Social Services Inspectorate publications (see Chapter 2).

The questionnaire was designed to create an employment history post-diagnosis and investigate the following themes:

- Why employment is maintained or relinquished

- Opinions and beliefs regarding employment

- Successful strategies and techniques employed for maintaining employment

- Utilisation of statutory/non-statutory services

- Post-employment activities

The selected question types were carefully considered as they had to elicit information relating to the chosen themes but at the same time avoid ambiguity and bias. To achieve this, a variety of question types were incorporated into the questionnaire including closed, open, list, category and quantity questions (Youngman 1986). The presentation of the questionnaire was important to engage participants, but font size, reading age analysis and amount of text was also taken into account. The questionnaire was ratified by the steering group and edited by one of the members who had previously been employed as an English teacher. A pilot questionnaire was created and completed by five volunteers from the steering group. This process was particularly important in order to assess the ease of use of the questionnaire for participants with impaired writing ability. In addition it was the most effective way of checking if leading, presuming, double and hypothetical questions had been avoided (Marshall and Rossman 1995).

The pilot participants reported that the questionnaire was straightforward and could be completed within the estimated 15 to 20 minutes, had good face validity and credibility. An initial analysis of the pilot responses confirmed that the questions were eliciting the data sought by this phase of the investigation. Only minor changes were required to the layout and the wording of two questions and then the questionnaire was ready for distribution.

4.2.3   Ethical Considerations

There are two main ethical perspectives to consider in this project. Firstly the overall approach to ethical issues and secondly the process of obtaining permission from an ethical committee to carry out this project.

It is well accepted that in any form of research consideration should be given to ensure that participants should not be harmed by the research and a range of procedures should be in place to ensure that participants understand the purpose of the research, the nature of their involvement and that consent to their involvement has been given (Bowling 1997, Marshall and Rossman 1995). Ethical principals are immersed in the methodological framework of this study and are integral to the whole process of data collection. The methodological framework that guides this study views participants as the experts in their condition, and it is this fundamental respect for participants that ensures that ethical issues are not only an explicit issue but also implicit in the entire construction of the study. In addition a researcher should be sensitive to the debt and obligation they have to the participants and should plan to reciprocate (Marshall and Rossman 1995, Scwandt 1997). In this study consumer consultation throughout the process ensures that people with PD have contributed to the design and the data collection with full knowledge of the reciprocity of the final product.

4.2.4 Ethical Approval Application

An application was made to the Northern and Yorkshire Multi-Centre Ethics Committee (MREC). An application to a local research ethics committee (LREC) or a Research Approval Board was not appropriate or required as the participants in the study were taken from a nationwide population and were not linked to a particular area or hospital Trust. At the time of the application the University accepted LREC or MREC approval without having to get additional approval through its internal process.

Preparing the necessary documentation for the MREC application was a difficult process. This study utilises a multi-methods framework which allows the methods and tools required for data collection to emerge during the research process. However an MREC submission requires all data collection tools to be presented in advance of their application to the participants. Resolving this conflict required the first data collection

tool (questionnaire) to be completed before the submission was made and an overview of the second data collection phase to be given. The submission was made and was viewed favourably with a few minor requests for clarification and amendment, these were made and full permission was granted.

4.3   Phase Two

4.3.1   Distribution of the questionnaire

Although the current estimate is 17,000 people with PD who are under the age of 50 in the UK, there is no national register of people with PD, so to construct a true sampling frame was not possible. In addition, access to younger people with PD has been found to be problematic in previous studies. A possible solution was to utilise members of the PDS but this would have created a bias and could not be considered to be representative of the target population. To try and ensure that the questionnaire was distributed as widely as possible and not only to members of the PDS, the assistance of the PDNS network was sought via the PDS which co-ordinates the network. At the time of distribution there were 170 PDNS employed in the UK. Their caseload consists of all age ranges of people with PD including those who are members of the PDS and those who are not. Most PDNS have a data-base of all individuals diagnosed with PD in their geographical 'patch' and based on population figures supplied by the PDS were likely to have between 2 and 6 individuals with early onset PD in their caseload. The PDS initially indicated that they would provide an address list of the PDNS, however they later decided that in order to comply with data protection laws they would be unable to send me the addresses of the PDNS but would be able to distribute the packs themselves.

A power calculation undertaken by a statistician indicated that taking into account a 50% return, 342 questionnaires should be distributed. The PDS were unable to create a sample of PDNS but agreed to send packs to each PDNS as part of their monthly mailing. It therefore seemed appropriate for the 170 PDNS to be asked to distribute 2 questionnaires each (as previously indicated, each PDNS should have between 2 and 6 people on their caseload who would meet the inclusion criteria) meaning that 340 questionnaire could potentially be distributed, so 340 packs were sent to the PDS via parcel force.

The packs sent to the PDNS contained:

- Letter of introduction for the PDNS (appendix A)

- Abstract of study (appendix B)

- 2 envelopes each containing:

  - a stamped self-addressed envelope,

  - a letter of introduction to the respondent,

  - two copies of the consent form (one for the respondent to keep) (appendix C)

  - an information sheet (appendix D)

  - the questionnaire (appendix E)

The PDNS were asked to distribute questionnaires to two people on their caseload who met the following inclusion criteria:

- A diagnosis of PD

- Have been diagnosed for at least 12 months

- Who are 50 years of age or less

- Who are willing to participate in the study

The letter of introduction to the PDNS requested that the questionnaires be distributed within 2 weeks and the letter to potential respondents which accompanied the questionnaire asked for it to be completed and returned within 2 weeks. Following this period, as the response rate was low, a letter was sent out to all the PDNS via the PDS network requesting that if they had not already done so, for the questionnaires to be distributed. After waiting another two weeks, and still having a low response rate, different strategies to distribute the questionnaire were considered and employed.

Following a conversation with the PDS Community Services Officer, she offered to distribute questionnaires to people who were attending the Younger Person's events organised by the PDS being held in Wales and the Midlands that month. Again, to comply with data protection, these were distributed by the PDS Area Officers in those locations, and the same pack contents were distributed to potential respondents.

To ensure that the questionnaire would reach as many people as possible, a third distribution strategy was utilised. A web-designer was employed to develop an on-line version of the questionnaire and following negotiation, the PDS agreed that a link could

be made from their website (see appendix F and G). This would allow distribution to people not known to the PDS or the PDNSs as anyone can access the PDS web-site. It would also enable people who prefer this type of media due to micrographia to participate. Although this method of distribution further extended the length of the first data collection phase it ensured that all possible means of distributing the questionnaire had been exhausted.

Following feedback from PDNS and direction from the steering group it was decided to remove the upper limit on the age of participants and to allow participants to be included if they had been diagnosed with young-onset PD even if they were currently over 50.

4.3.2 Approach to analysis

The analysis plan for the data collected using the questionnaires needed to take into account both qualitative and quantitative responses. The quantitative data was analysed using the SPSS programme (Version 11) to create descriptive statistics. Qualitative data was coded and analysed thematically using the computer-aided qualitative data analysis software program NUD*IST (QSR 1994). In addition, some of the qualitative responses were transformed i.e. categorised, coded thematically and converted into quantitative data, this produced particular insights into the change of leisure activities post PD.

For the majority of responses descriptive statistics were produced, but further analysis was undertaken with some data to consider variance and significant difference. Analysis of the questionnaire responses will be presented in the following chapter and can also be in appendix K.

4.4 Phase Three

4.4.1 Focus groups

Initial analysis of the questionnaires was undertaken and the results presented to the steering group for their consideration. This was an essential stage in the process as the low response rate to the questionnaire may have resulted in inadequate data collection at this point and an alternative strategy employed for further data collection utilising this method may have been required. However, it was immediately apparent that there was a

large degree of consensus within the results of the questionnaire despite the response rate being less than required, and it was time to move onto the next stage.

Focus groups were identified at this stage in the sequential approach to data collection for two reasons commonly described in research literature; firstly as a method of obtaining immediate feedback, perceptions and interpretations or validation regarding the results of the questionnaire (Vaughn et al 1996), and secondly as an additional data collection method with immediate 'within group' consensus (Morgan 1993). Although traditionally focus groups are not used as a method of validation, they have often been used to triangulate data alongside other methods (Vaughn et al 1996). In this study they were used for dual purposes and the primary use being (feedback and validation) influential in the application of the second (further, more in-depth data collection). In relation to data collection, the type of data required from the focus groups is different to that required from the questionnaire. Focus groups allow the collection of opinions, priorities and understanding of topics and recurrent experiences. Discussion can be stimulated and therefore topics can be examined in greater depth with the goal being to elicit perceptions, feelings, and attitudes (Bowling 1997, Vaughn et al 1996, Marshall and Rossman 1995). It is this depth of understanding that was required at this stage in the study.

The use of focus groups as a data collection method is compatible with the philosophical assumptions in the methodological framework of this study, as multiple views of reality and diverse opinions can exist and that these views and opinions are influenced by individual perspective (Vaughn et al 1996). In addition, focus groups can be employed when a 'friendly' research method is required, one that is respectful and not condescending. They are used to ascertain the perspectives of key stakeholders and are considered to be a powerful means of exposing clinicians and researchers to the knowledge gap surrounding the reality experienced by their patients bringing the researcher in direct and intense contact with them. A focus group can allow for a 'human connection' between subject and researcher and having direct contact and conversations with subjects can enable critical understanding of a topic (Vaughn et al 1996, Morgan 1993).

Although there was considerable agreement in the questionnaire results, a major part of the study was to learn more about the range of opinions or experiences that people with PD have regarding employment. Focus groups have a strong advantage here because the interaction in the groups can provide an explicit basis for exploring this. Unlike most

structured interviews or surveys, participants in focus group interviews have the opportunity to clarify, extend, and provide examples yielding unambiguous information about what participants actually think (Vaughn et al 1996, Morgan 1993).

Focus groups can also be used to learn more about the degree of consensus on a topic (Morgan 1993). However it should not be assumed that the goal is to generalise to larger populations, rather the goal with focus groups is to describe findings and gain convergence on a particular topic or situation, not to elicit principles or make inferences that can be extended to a wider population. Due to the sampling strategies used for focus groups rarely being random selection, it is not possible to make inferences from the data to a larger population due to the bias of the sample selection (Patton 1999). However, the focus groups will yield information rich data which will illuminate the specific situation being studied and enable transferability rather than generalisability at this stage. Credibility of results will be achieved in this study through the rigour of the data collection methods and through utilizing triangulation (Patton 1999).

Usually additional data collection methods are used to follow up the initial findings from the focus groups to establish if there are any transferable findings (Vaughn et al 1996), this will be undertaken in this study with the addition of a third data collection tool.

4.4.2 Planning the focus groups

Several themes were identified from the initial analysis of the questionnaire that required further investigation. These were endorsed by the steering group and a focus group schedule was developed to enable further exploration. The schedule was discussed by the steering group to ensure that the prompts or questions associated with the themes were sensitive and appropriate for a group setting. The steering group then approved the schedule (appendix H).

Although usually focus groups are conducted using participants who do not know each other, in this study, established groups were utilised for pragmatic purposes. During initial consultation with the PDS, it was suggested that the researcher attend a series of events for younger people with PD organised by the PDS, and that focus groups could be held at these events. However during attendance at the first of these events in the Midlands it was discovered that this information had not been passed to the event organiser and therefore the focus groups did not go ahead. As an alternative strategy the

PDS Community Services Officer identified several groups of younger people with PD who met regularly on a semi-formal basis in a self-help capacity. These groups were contacted by the Officer and the members of three of these groups (in the South Yorkshire and Midlands area) agreed to allow one of their monthly meetings to be utilised as a focus group, and the contact details of the informal 'chair' of these groups was given to the researcher. Generally focus group size is between 6 and 12 participants (Bowling 1997, Vaughn et al 1996) however, due to the circumstances there was little control over the numbers attending, and the groups stated that they usually had between 10 and 20 members attending which included spouses. This use of purposive sampling in established groups was viewed as an advantage in the process. Usually when commencing a focus group, the facilitator (person conducting the group) has to establish group cohesiveness and trust as sometimes the lack of confidentiality within the focus group may be inhibiting particularly when talking about a disability or illness. However, these groups were used to talking about their condition and therefore issues surrounding disclosure were avoided. Despite the groups requiring less work to set themselves at ease with each other, they still needed to establish trust and rapport with the researcher who was facilitating the groups. This was achieved by being transparent about the researcher's background and the purposes of the study, articulating a thorough understanding of the research aims and describing the involvement of the Steering Group and consultation with the PDS. These initial discussions reflected the study's philosophical framework in reinforcing that participants were valued contributors to the research and essential to the understanding of the research topic. This was also one of the reasons why an external moderator was not used to facilitate the focus groups as the philosophical framework encouraged close contact between the researcher and participants. Despite some of the initial problems in organising the groups, the approach, driven by the philosophy of the study was successful in achieving the desired response from the groups. The groups appeared and behaved at ease with each other and the researcher and responded well to the focus group schedule tackling all themes with openness and directness.

A key feature in the success of a focus group is the skill of the facilitator in directing the group and achieving the research objectives. The facilitator must combine the skills of effective interviewing (eliciting the required information and promoting disclosure) with group processing skills (achieving group cohesiveness and progression). In this study, the researcher was trained and experienced in group processing skills through

post-graduate courses and clinical work, and was a skilled interviewer in both research and clinical settings.

The first focus group took place in the home of the Chair of the group, the other two groups met in hired halls all of which were the usual meeting locations for these groups. A Focus Group Implementation Schedule was used (see appendix H) with all three groups which included statements on:

- Confidentiality

- Consent

- Comfort and interruptions

The groups were audio-tape recorded using an active power zone microphone. Following each group a Contact Summary Sheet was completed.

4.4.3 Undertaking the Focus Groups

Themes that emerged from the questionnaire were utilized to create the Focus Group Schedule (appendix H). Three focus groups were carried out across North Yorkshire and the Midlands, with each focus group having between 10 and 16 participants. In two of the focus groups, participants arrived late once the group had started and joined in, so numbers were not exact but approximately 40 people in total took part in the focus groups.

4.4.4 Approach to analysis

Contact Summary Sheets were completed following each focus group which recorded the researcher's initial thoughts about the group such as interesting themes, agreements or disagreements between respondents (appendix M). The sheet also recorded the date, location, and basic details of the group, including any interruptions, difficulties or disturbances. The focus groups were audio taped using an Active Pressure Zone Microphone for clarity. The audio recordings of the focus groups were transcribed and then checked for accuracy. The transcripts were then transformed into a format for analysis by the computer-aided qualitative data analysis software program NUD*IST (QSR 1994) to facilitate thematic analysis. The data was then analysed using two types of category structure, factual and referential. This enabled powerful and detailed

searching of the data, creation of a thematic coding structure and theory development. The formation of the initial coding structure was checked by the researcher's supervisor. Thematic analysis was employed to make sense of the variety of approaches used to record the experiences of the respondents and also to structure reflexivity within this analysis process, participants were able to consider both the data and the interpretation of the data made by the researcher (Burr 1995).The results of this initial analysis were presented to the steering group for their consideration before moving onto the final stage of data collection.

4.5 Phase Four

4.5.1 On-line collection of stories

The final approach to data collection utilised the most creative method employed in this study. Multi-method research has often been acknowledged as the catalyst for the development of inventive, creative and ingenious methods to collect data. However the development of a creative data collection tool was approached with a degree of caution, as due to having a mixed-methods design it was imperative that all the data collection tools not only informed the study but held a consistent ontology and epistemology true to the theoretical framework of the study (Blaikie 1991, Creswell 2003, Ritchie and Lewis 2003).

As with the preceding data collection phase, this phase was guided by the initial analysis of previously collected data. The results from both the questionnaire and the focus groups were considered by the steering group and although these two data collection methods had yielded good quality results with a high level of consensus and saturation, it was felt by both the researcher and the steering group that a further stage was required to 'close the loop' by both validating the existing research themes and gaining meaningful propositions and deeper insight into these themes.

Initial analysis of these phases indicated an emerging 'story' or narrative account of the influence of PD on employment. Although narrative accounts have traditionally been used in single method qualitative approaches they can also be constructed from quantitative data gathered in a structured way (Robson 1993) and can occur in multi-method designs. Narrative research has produced a process described as 'The Narrative Turn' (Czarniawska 2004) in which stories are 'provoked' by the researcher then go through a process of being analysed and deconstructed before being set against other

stories. In this study the previously gathered data or 'stories' were deconstructed and an emerging narrative account formed. This was discussed by the Steering Group and validated with their own experiences and it was then decided that the narrative account could be used as a data collection tool. This would enable specific data collection to further validate previously collected data and gain a deeper insight of the research topic. The results of the first two data collection methods highlighted seven key themes which constructed the narrative account. These themes relate to the 'epiphanies' described in narrative research around which an individual's identity is constructed (Denzin 1989). An epiphany can be defined as a sudden realization or a leap of understanding which leaves a mark on a person. Epiphanies structure the sequence of our lives and are identified by the significance that is attached to it, for example disclosing the diagnosis of PD to an employer.

The themes from the narrative account were supplemented with prompt questions and a proforma was developed (appendix I). It was structured in a way that would facilitate the respondent to disclose the relevant information in the form of a personal history. Counter narratives were also included for example *"what I should have done"* which are useful to guide responses when taking a retrospective stance, as is the case for many respondents. Creating this proforma to gather an employment narrative utilising the prompt questions was essential as often the most important stories are the ones that people are unable to tell (Denzin 1989). Experiences may seem random and discontinuous to the individual unless they are prompted and guided to express them (this difficulty in describing the experience will be examined further in the following chapter). In this situation it was appropriate for the researcher and the steering group to develop the proforma as the autobiographical background to the topic was understood and being steeped in the context would mean the researcher was highly sensitised to the data and able to interpret.

Due to the close collaboration with the PDS throughout the whole research project the opportunity to again use the PDS web-site as a data collection method was offered. In collaboration with the web-designer a site was developed to house the proforma and a submission system installed to allow younger people with PD to contribute their experiences of employment for a time limited period. A link from the PDS main site and the web-management system allowed for a link to a site to be set up without having to buy an additional domain name, and also served as a prompt to visitors of the main site.

This was an excellent use of available resources and technical support and provided an innovative data collection media that was appropriate to the age of the sample group. Prior to being launched on-line, the proforma was displayed to younger people with PD attending the annual PDS Younger Person's event (YAPMEET 2004). The feedback from this group was very positive regarding both the need for information relating to employment and the layout of the proforma.

The launch of the site was advertised to the network of local group contacts, through an article in 'The Parkinson' magazine (sent to all members of the PDS), a flier to branches from the web-manager and via contacts made during the course of the project (appendix J). This was left open for contributions for a fixed time period of two months.

4.5.2 *Approach to analysis*

An issue that was both a strength and potentially a weakness in this data collection phase was that there was no control over the sampling utilised in this method. Although inclusion criteria were stipulated on the site, participants would be self-selecting. However, one of the benefits was that the PDS site is accessible to people who are not members of the PDS and although the PDS site is UK orientated, the World Wide Web is indeed international and unexpectedly responses were received from as far afield as America and Canada, perhaps indicating that the research topic had international interest.

The data collected using this tool required an approach to analysis that was sympathetic to the narrative methodology utilized in its construction. Demographic details were initially gathered and the responses collated (appendix L), then two forms of analysis were applied. Firstly the stories were categorized by question to ascertain if there were any similarities in the narrative themes indicated by the tool. Secondly the submitted stories were transformed into a format for NUD*IST (QSR 1994) and added to the data set initiated in the previous data collection phase for further thematic analysis. As the purpose of this stage was to validate the emerging narrative account and gain further insight into the identified themes, an additional data analysis method was not required. The submitted stories were treated as verbatim transcripts and utilising NUD*IST (QSR 1994), analysis was carried out by employing the coding structure created in Phase Three. The themes established in the previous phase were then confirmed or alternatively rejected using the new data and a final coding structure was created

(Tables 7, 8, 9 and 10). To facilitate the analysis an understanding of the language used by participants and the context of the experience was essential in the interpretation of the results. This was achieved through the researcher being a practitioner and having considerable experience and insight into the condition. The researcher was therefore able to interpret the results in relation to previous clinical situations.

4.6 Validation

Validation of the chosen methodology was discussed in the previous chapter, and in the introduction to this chapter, however a further examination of validation is now appropriate. Validation strategies were used within the analysis of the data to check the accuracy of the findings. In addition to the cyclical validation of the data collection process, each separate data set was validated appropriately in terms of accuracy of analysis procedure. Two statisticians verified the SPSS analysis results of the quantitative data and an experienced qualitative data analyst verified the NUD*IST codings and content.

4.7 Conclusion to Methods Chapter

This chapter has described the range of tools and techniques used to collect data in order to answer the research aims proposed by this study. A sequential transformative strategy has been presented which guides a multi-method approach to data collection and reflects the ontology and epistemology of the theoretical framework. Collaboration with the PDS has allowed for some innovative data collection methods to be developed and implemented.

The involvement of consumers and other stakeholders has been described and the guidance of the Steering Group has been invaluable serving to diminish the effects of researcher bias, therefore the description of the employment experience of younger people with PD should be credible, will have meaning for this group and will fulfil the first research aim of this study and the associated objectives:

1) To understand the employment experience and trajectory of younger people with PD

i) Explore the meaning of occupation for younger people with PD

ii) Identify the aspects of work that may be beneficial to someone with PD

iii) Understand the strategies used for maintaining work by people with PD

iv) Appreciate the decision making process utilized by younger people with PD when choosing to remain in or leave work.

One of the major strengths of this study lies in the transparency of its design and obvious face validity. Continual validation of the data both with the steering group and through the responses and reactions of participants to the data collection methods will ensure that the results described in the next chapter have both a real world meaning for people with PD and a clinical application. The approach to the interpretation of results follows the creative trend established in this study and fulfils the second research aim:

2) To model an intervention to assist people with PD to maintain employment.

The following chapter will present the findings of the data collection methods described in this chapter.

5 Findings

This study was directed by a clinical question which was influenced by the professional beliefs and practices of the researcher. The social and cultural concepts of the experiences, in addition to the impact of those experiences, on the individual were collected. The approach to data collection adopted in this study has demanded insightful interpretation of the results (Jick 1979, Creswell 2003). In this chapter a description of the respondents in each of the data collection methods will be described, the results of the data collection presented and the emergent themes highlighted. In the following chapter (Chapter 6) the results will be presented in the context of an emergent intervention.

5.1 Data Collection Method 1 - Questionnaire
5.1.1 Description of Questionnaire respondents

Out of 400 questionnaires that were distributed, 60 responses were received. The sources of the responses can be found in Table 2.

Table 2 - Description of the source of Questionnaire responses

Questionnaires distributed by PDNS	29 (48.3%) *
Questionnaires distributed by local groups	21 (35%)
Questionnaires submitted on-line	10 (16.7%)**
Total number of responses received	60 (100%)

* One response was from somebody who had already reached retirement age when diagnosed and was therefore not included

** An additional 3 questionnaires were submitted after the analysis commenced and were therefore not included.

The data received from the three sources was examined to discover if there were any major discrepancies in the groups. One-way analysis of variance was carried out on the 3 groups in regard to age, gender, years diagnosed and age diagnosed, the post hoc test used was DUNCAN. There was a significant difference in relation to current age and

age diagnosed but there was no difference in the groups regarding the number years they had PD or gender. The questionnaires distributed by the PDNS and those completed online responses were from younger people than the respondents from local groups. A description of the questionnaire respondents can be found in Table 3.

Table 3 - Description of Questionnaire respondents

	Range	Mean
Current age	31 – 67	51
Age when diagnosed	28 – 59	44
Years had PD	1 – 19	7.2
Sex of respondents	65% Male	35% Female

5.1.2 Results of analysis - Questionnaire

The quantitative data from the questionnaire responses was analysed using the SPSS programme (Version 11) to create descriptive statistics. In addition some of the qualitative responses were transformed i.e. categorised, coded thematically and converted into quantitative data, this produced particular insights into the change of leisure activities post PD. For the majority of responses descriptive statistics were produced, but further analysis was undertaken with some data to consider variance and significant difference. A full analysis of all the questionnaire responses can be found in Appendix K. Analysis of the questionnaire responses relating to respondents' experiences of employment can be found in Table 4.

Table 4 - Descriptive statistics of Questionnaire responses relating to employment

	Range	Mean		Standard Deviation	
Age left work	30 – 59	48.3		7.29	
How long following diagnosis left work? *(in months)*	1 – 168	43.5 *(3.6 years)*		40.58	
How long following diagnosis did you inform your employer? *(in months)*	0 – 48	3.6		8.86	
Years lost in employment due to PD	4 – 35	13.5		7.15	
Currently in employment?	38.3% Yes	61.7% No			
Left work due to PD? (if currently unemployed)	92% Yes	8% No			
Type of job	Professional 13%	Managerial and technical 52%	Skilled occupation 23%	Partly skilled occupation 10%	
Reason for giving up work (some respondents gave more than one reason)	No answer given 45%	Employer's medical requirements 7%	Physical reasons 45%	Psychological reasons 23%	Lack of understanding from workplace 8%
Would you liked to have remained in employment?	No answer 9%	Yes 65%	No 23%		
Did or have you adapted your working arrangements?	No answer 12%	Yes 43%	No 45%		
Any benefits of remaining in employment?	No answer 5%	Yes 75 %	No 20%		
Have you sought assistance to remain in employment?	No answer 2%	Yes 40%	No 58%		
Did you receive any assistance to remain in employment?	No answer 8%	Yes 37	No 55%		
How successful was the assistance?	No answer 14%	Very 55%	Moderately 27%	Not at all 5%	

The questionnaire also considered respondents' leisure activities, these questions were included to gain a picture of younger people with PD's work –life balance. The leisure activities identified by the respondents were converted into groups of activities for ease of analysis. The groups were:

- Sport – including football, running, walking, gym attendance, golf
- Voluntary work – including charity, church and school groups
- DIY/Gardening – including decorating and allotments
- Social activities – including dining out and meeting friends
- Sedentary hobbies – including computer based activities such as family tree research and reading
- Travelling – including day trips, short breaks and holidays

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- Creative activities – including craft work and painting
- Further education – including distance learning and night classes

The reported hours spent engaging in these activities pre and post a diagnosis can be found in Table 5.

Table 5 - Time spent on leisure activities prior to and post diagnosis of PD

	Mean number of hours undertaken per week prior to PD	Mean number of hours undertaken per week post PD
Sport	5	2
Voluntary work	0.4	1
DIY/Gardening	2.2	1.6
Social activities	4.1	1.4
Sedentary hobbies	1.3	7.3
Travelling	1.6	1.2
Creative activities	2.8	2.5
Further education	0.5	0.1
	Total hours spent per person on leisure activities prior to PD = 17.9	Total hours spent per person on leisure activities prior to PD = 17.1

The paired sample t-test was carried out and found no significant difference between pre and post PD in total hours spent on leisure activities. Again, the Wilcoxon test found no significant difference, whilst medians change it was not significant due to the spread of data.

It was surprising to note that the number of hours spent engaged in leisure activities remained virtually the same between pre and post diagnosis, even though 60% of the respondents were now out of work and had left work due to PD. As clinical experience indicated that people with PD become less physically active and more socially withdrawn following diagnosis, the activities listed by the respondents were categorised into active (sporting) or sedentary (computer based) activities and

further into social (with other people) or solitary (carried out alone) activities and can be found in Table 6.

Table 6 - Hours spent in categories of leisure activities

	Mean number of hours undertaken per week prior to PD	Mean number of hours undertaken per week post PD
Active social	4.77	2.37
Active solitary	5.78	3.68
Sedentary social	3.75	2.75
Sedentary solitary	3.15	9.18

When comparing the difference between activities pre and post PD (t-test) there was a significant difference in sedentary hobbies, social activities and sport. An increase in sedentary hobbies from 1.27 to 7.3 hours, a decrease in social activities from 4.12 to 1.37 and a decrease in sport from 4.95 to 1.98. The reasons for giving up leisure activities were; physical reasons such as fatigue, stamina, tremor (82%) psychological reasons such as embarrassment, motivation, confidence (33%) and other such as transport, time and financial (13%). Only 17% of respondents sought help to maintain their leisure activities although 87% of respondents stated that they thought that maintaining leisure activities was beneficial. Those benefits were seen as being; physical fitness (55%), self-confidence (27%), mental stimulation (42%) and social contact (28%).

5.1.3 Observations to explore and expand on in subsequent data collection

Following initial consideration of the data from the questionnaires, the following significant themes emerged that required exploration in the focus groups.

- Only one questionnaire respondent stated that he/she had found out about employment assistance from the PDS Welfare Officer (or anywhere else from

the PDS). Is there a lack of information available, or, do people with PD not know where to find it?

- Respondents tended not to seek help to retain their employment and did not receive help to retain employment.

- Specific symptoms are emerging which cause problems at work.

- Some respondents stated that holding down a job was causing them to be so fatigued to that they were unable to maintain their leisure activities.

- There was a huge change in types of leisure activities engaged in post PD. Social and active activities decreased. If someone leaves work and their leisure activities are solitary then they may become socially withdrawn.

5.2 Data Collection Method 2 – Focus Groups

5.2.1 Description of Focus Group respondents

Participants in the focus groups were not all asked to state their age. However the participants self-selected themselves to be in the focus groups by using the inclusion criteria which stated that they should be of working age. The youngest participant declared herself to be 34 so therefore the participants ranged between 34 and 65 approximately. There was a mix of people currently working and those who had given up work. In this stage of data collection, unlike the other two methods, spouses participated, giving additional depth to the data collected, although when analysing the data, the voice of the person with PD was prioritised over the spouse.

5.2.1 Results of analysis – Focus Groups

Contact Summary Sheets were completed following each focus group which recorded the researcher's initial thoughts about the group such as interesting themes, agreements or disagreements between respondents (appendix M). The recordings of the focus groups were transcribed and the transcripts were then transformed into a format for analysis by the computer-aided qualitative data analysis software program NUD*IST (QSR 1994) to facilitate thematic analysis.

A coding structure was developed from the focus group responses. An initial coding structure was developed which identified the data surrounding the impact of PD on

employment and leisure. A second coding structure contained data related to the impact of PD on leisure activities. A further coding structure was developed from the data surrounding the interventions requested and received relating to the maintenance of employment. Theory development prompted a forth coding structure which used the data relating to the impact of knowledge, attitudes and actions on an individual's experience of employment. These coding structures were later populated by data from all of the data collection methods and can be found in tables 8, 9, 10 and 11.

5.2.2 Observations to explore and expand on in subsequent data collection:

Following initial consideration of the data from the focus group, the following significant themes emerged that require exploration in the next data collection method.

- There was a sense of regret about having given up work. Participants reflected that perhaps they should not have given up so soon

- The participants seemed to be unable to specify particular reasons why they gave up work although certain symptoms continued to be mentioned

- The lack of sources of help to maintain work continued as a theme

- A surprising number of participants stated that they did not tell their colleagues or even their employer

- Very few participants made adjustments to their work to enable them to stay in work longer

- Respondents had very little knowledge of relevant employment legislation

5.3 Data Collection Method 3 – Online Stories

5.3.1 Description of On-line Story respondents

Twenty seven stories were obtained using this method but only twenty were analysed. Three were submitted after the closing date and once analysis had commenced and four were only very partially completed so were rejected. Although inclusion criteria were stipulated on the site, participants were self-selecting. The PDS site is accessible to people who are not members of the PDS and although the PDS site is UK orientated,

unexpectedly responses were received from as far afield as America and Canada, indicating that the research topic has international interest.

The mean age of respondents was 51 years, the age of onset of PD was 46.6 years and the mean age of leaving work was 49.5, this indicates that the 8 respondents who were no longer working were likely to have left work less than 3 years after being diagnosed. There was a higher number of 'working' respondents in this data collection method than in the questionnaire (60% in this method and only 38% in the questionnaires). Further demographic details can be found in Table 7.

5.3.1 *Results of analysis – On-line Stories*

Demographic details were initially gathered and the responses collated, then two forms of analysis were applied. Firstly the stories were categorized by question (appendix L), to ascertain if there were any similarities in the narrative themes indicated by the tool. Secondly the submitted stories were treated as verbatim and transformed into a format for NUD*IST (QSR 1994). They were then used to further populate the coding structures developed in the previous data collection phase and small adjustments to the coding structure were made when this additional data was considered. Tables 8, 9, 10 & 11 illustrate the coding structures which have been populated with examples of the qualitative data taken from the focus groups and on-line stories. For ease of viewing the coding structure relating to employment has been split and distributed between two tables.

Table 7 - Demographic details of the On-line Story respondents

Respondent Number	Age	Diagnosis Age	Working	Age left work	Job
1	51	47	no	51	Civil Servant
2	58	56	yes	-	Manager of housing for adults with learning disabilities
3	45	44	yes	-	Occupational therapist
4	50	45	yes	-	Horticultural consultant
5	49	49	yes	-	Auditor
6	52	44	no	50	Medical Receptionist
7	51	54	yes		Civil servant
8	42	40	yes		Development worker
9	34	30	no	30	Engineer
10	54	51	yes	-	Account manager
11	66	55	no	65	Credit control
12	46	39	no	45	Middle school teacher
13	53	47	yes	-	Cashier
14	57	53	no	55	Train driver/operator
15	50	43	yes	-	Teaching assistant
16	55	51	yes	-	Word Processor Operator
17	48	47	no	48	LGV driver
18	49	39	yes	-	Business centre manager
19	61	51	no	52	University Administrator
20	52	47	yes	-	Management consultant
	Mean age: 51.15	Mean age of diagnosis: 46.6	Working: 12 Not working: 8	Mean age left work: 49.5	

Table 8 – NUD*IST populated thematic coding structure relating to impact of PD on employment

Impact of PD on employment	Stayed	Job description	
		Descriptive statistics from questionnaire and on-line stories	
		"I should have done it [become self-employed] earlier! I'm very happy that I retained control over events - and that I have more clients than ever." (S20)	
		Employer's response	
		"Basically honesty is the best policy. Respect for my colleagues and boss." (S15)	
		"They [employer] have been brilliant and extremely supportive." (S3)	
		Financial implications	
		"[if left work]I would be unable to afford leisure activities or to buy things for my garden; a crucial part of my survival both physically and mentally!" (S2)	
		Supportive strategies	
		"My GP and PD Specialist nurse have been brilliant as has the consultant and local Occupational Therapy lady." (S7)	
		"I now work from home on days I am not on the road this arrangement was to a large extent co-incidental however I am able to take advantage of the flexibility especially first thing in the morning when I haven't got any flexibility!" (S10)	
		Difficulties experienced	
		"I feared the worst that I may lose my job or status. I also thought… it's none of their business anyway!" (S8)	
		Why stayed?	**Symptoms**
			"My condition at present is fairly mild and particularly as I live alone I feel that working keeps my brain going." (S10)
			Personal attitude
			"…I also want to develop my career. Having Parkinson's doesn't change your aspirations or needs." (S8)
			"Teaching was me I was teaching, rightly or wrongly it became me, and therefore I was no longer that me anymore." (FG3R1)

Table 8 continued

	Job description	
	Descriptive statistics from questionnaire and on-line stories	
	"I was a self–employed heavy goods driver I carried on for 3 yrs and I decided to pack it in because I didn't feel safe." (FG3R11)	
	Why left?	**Symptoms**
		" … it's the voice because you sound sort of bored less enthusiastic." (FG2R2)
		"I realised that I was making typing mistakes and my handwriting, when taking telephone messages, was getting smaller and smaller." (S19)
		"By the end of the day I had pains in the back of my neck." (S20) "Unable to, concentrate and carry out client interviews, memory loss and confusion also impacted on my ability to carry out my duties." (S1)
		"I found difficulty speaking when stressed or tired." (S20)
		"I type alternatively very slowly or very quickly depending on the time of day. I can't go to meetings that are the wrong time of day for me, some people understand, others don't." (FG1R2)
		Justification for leaving
		"I had a good offer…they were getting rid of people …I would have to leave eventually anyway" (FG1R3)
		"I could see myself being made redundant if I didn't retire…" (FG3R6)
Impact of PD on employment	**Left**	**Employer's response**
		"On diagnosis, the occupational nurse nearly had a coronary until I got the letter from the DVLA saying I was fit to drive." (S17)
		"…when I told them they didn't suggest any changes and sent me to see the doctor and he was more or less the same you can't work like that and that was it." (FG2R3)
		Financial implications
		"I dropped £600 per month on leaving." (S1)
		Positive aspects of leaving
		"I knew that I could be a better father and husband if I retired." (S12)
		"….by the time I got home I was cream crackered and my home life was going down the drain. I was just exhausted, that was mainly the reason why I left in the end." (FG2R4)
		Negative aspects of leaving
		"Disappointed [when gave up work] in as much as I enjoyed the camaraderie of the office and of the clients." (S11)
		"Made me feel a lesser person, affecting my self esteem." (S1)

Table 9 – NUD*IST populated thematic coding structure relating to impact of PD on leisure

	Time spent
	Analysed data from questionnaire
	Type of activity
	Analysed data from questionnaire
	"I would like to try voluntary work but I think that would affect my benefits if you do voluntary work. I think you might not get your benefits, I find that really restricting." (FG2R4)
	"Not on the scrapheap yet but I have taken on unpaid jobs in society which is the grey matter still ticking over and just getting involved in things where I can. I have become more computer adept." (FG1P1) *"I don't have many leisure activities if I have time I usually get home [from work] and play on my computer, bit sad really."* (FG1P2)
Impact of PD on leisure activities	**Adaptation**
	"I just can't do what I used to, I no longer have the physical energy to go to exercise classes after work or the Gym. I found that work took all my stamina with nothing left for the family. Therefore, I have increased my medication to give me a boost in the evening so my family don't just see the 'dregs'!" (S8)
	"Just cut down on my spontaneous events as I now need a little more pre-planning." (S11)
	Work/life balance
	"...also the stress of keeping yourself going that spills over into the evening when you continue to be stressed and anxious." (FG3R1)
	"[maintaining work has a] Massive impact [on other activities]. I just can't do what I used to I no longer have the physical energy to go to exercise classes after work or the Gym. We don't socialise much!" (S8)

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Table 10 – NUD*IST populated thematic coding structure relating to sources and types of interventions for employment

	Information intervention	Tangible intervention
	NHS "…the Doctor said you're not well enough to work or do the job so she wrote me a 3 months sick note and that was it." (FG2R2)	**Change role** "…got to the stage where I couldn't handle anything and then I got to the stage where I couldn't stand up for very long without falling. So my job moved to a desk." (FG2R6)
	HR/employer "Colleagues offered help with all kinds of tasks that I had to do. My bosses couldn't have been more helpful, allowing me to tone down my stress level by changing jobs 3 times in a 5 year period." (S12)	**Flexible hours** "I have flexible working arrangements regarding time and work venue. I get assistance if I'm going to travel long distances ie I take the train not driving. I receive time off to attend appointments; hospital, GP, physio." (S8)
	Financial "I don't feel that that type of advice [financial] is out there and I feel that wherever you go people tell you your entitled to this or to that and if you do that there are two options that this might happen or this there again this might happen but for us we can't take that risk." (FG1R2)	**Equipment** "They were very good at work, got me an occupational therapist, got me all sorts of special equipment." (FG2R4) "An automatic car also fitted with a modification to allow use of indicator from both sides. I could have had further modifications but do not require them." (S10)
	Schemes/policies "I have good knowledge of my employment rights. However, if I become more incapacitated, I think I will find it difficult to 'work the system'." (S2)	
Sources and types of assistance	**Signposting** "Got employment support from Access to Work." (S1)	**PDS** "PDS Helpline were wonderful." (S14) "I have the PDS employment information." (S3) **Other** "I went to see the Disability Employment Adviser at my local job centre." (S17)

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Table 11 – NUD*IST populated thematic coding structure of theory development

Theory development	**Employer**	**Knowledge**	**Positive** "[My employers were] excellent. They spoke to me prior to the interview to assess my requirements. Candidates were to be given a presentation on the day to deliver, following discussion about slowness and size of handwriting this was changed. All candidates were given the topic in advance." (S8)
			Negative "Employment departments are not always helpful, and try to offer menial jobs. Just because I wanted less hours, did not necessarily mean that I was not capable of doing my job properly." (S18)
		Attitude	**Positive** "As they had noticed something badly amiss, they [employer and colleagues] were relieved when I gave them my diagnosis. I have received nothing but understanding and their unstinting support." (S7)
			Negative "Fear! Most employers think that you will immediately start shaking and falling about. They often think that your mental capabilities are automatically affected. When I needed to change jobs (moved area) because I was not applying for management positions (I felt I wanted less pressure) and I explained why although given an interview, I sensed that I was not going to get the job." (S18)
		Actions	**Positive** "Occupational Health have turned out to be very useful, directing my manager to be flexible in working time and in allowing me to work from home." (S8)
			Negative "Yeah, if they had said to me would you like to come in later in the mornings then this would have been a great help." (FG2R3)
	Employee	**Knowledge**	**Positive** "I think I have a pretty good grasp of my rights. In order to fire me the district would have shown over a period of time that I couldn't do my job. They would have needed to adjust my working situation as it became necessary." (S12)
			Negative "Research all aspects of employment rights. Check out your pension. Mine doubled if I had contributed for 5 years and left through ill-health!" (S6)
		Attitude	**Positive** "I needed to keep working …to avoid becoming terminally bored." (S20)
			Negative "I fell up the stairs twice, lurched about a bit, I felt down in the job not doing it properly, pride was an issue." (FG3R3)
		Actions	**Positive** "I do tasks at a time appropriate to how I am. i.e. It's not ideal to take the coffee out to a teacher on playground duty when I know I am having a bad patch, or trying to put tights/socks on a child after PE." (S15)
			Negative "I feel a lot more tired when I get home from work in the evenings than I used to and this has reduced the things I do outside work." (S5)

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5.3.2 *Observations from On-line Story data collection*

Following initial consideration of the data from the stories, the following significant themes emerged.

- Respondents who had disclosed their diagnosis to their employer and colleagues seemed to have made a successful adjustment to managing their employment

- Adjustments made were relatively minor and easy to implement but had made a considerable difference

- Knowledge of relevant employment legislation again was poor

5.4 Conclusion to Findings Chapter

This chapter has presented the results of the three data collection methods used in this study. A thematic trail through each of the data sources has been described. The thematic coding structure used to analyse the qualitative data from two of the data collection methods has been established, and examples of the population of the coding structure given.

The following chapter will present these results through the eyes of a practitioner. During the process of data analysis, in order to achieve an understanding of the impact of this data on practice, a theory personal to this investigation was created from which a clinical intervention was developed. The researcher discovered that following the collection of the data, she was applying the knowledge of that data in her clinical practice. The narrative that she was using in practice was one borne out of those heard in the research, and she gained a deeper understanding of the results through living them and then transferring them into her clinical practice. She consequently realised that the results would have more meaning to her and be directly applicable to this client group if they were organised in the form of an evidence-based, clinical intervention which is presented in the following chapter.

6 Seven Stage Intervention

6.1 Overview of chapter

The collected data enables a depth of understanding of the employment experience of younger people with PD. This chapter will present the results in a manner consistent with the theoretical framework. The research aims were derived from a clinical question so to fulfil the research aims, the results and the discussion of the results will be presented as a clinical intervention. The intervention consists of seven stages (Table 12) and this chapter will follow these stages in sequential order. The seven stages of the intervention are all of differing lengths which reflects the nature of the intervention and although the intervention has been divided into these seven stages, some overlap and repetition will be noticed as the iterative nature of the intervention encourages the person with PD to consider issues, and, to return to them at different stages within the intervention. Each stage focuses on key themes which inform the context and clinical application of that stage. The themes were generated from the analysis of the collected data. The type and quantity of presented data within each stage differs, with some stages having a greater number of themes (Table 12), or being evidenced predominately by one type of data. It is not the purpose of this chapter to present the entirety of the analysed data, rather, selected data has been used to illustrate the themes within each stage of the intervention to enable the reader to understand where the theme has arisen from, and, its relevance within that stage.

Each stage of the intervention will be presented in a similar format consisting of the following:

1. **Clinical Reflection** - of the researcher's own experience which prompted formulation of that particular stage

2. **Themes arising from the data** - results from all of the data collection methods presented in themes and illustrated by quotes or descriptive statistics

3. **What the literature says** - which supports or further evidences the themes in that stage

4. **Intervention** - a description of the purpose of the intervention and how it will be delivered.

The idea for the intervention originated from a clinical question, and with each stage of the intervention containing a reflection on practice, it seemed appropriate to present the Clinical Reflection section and the Intervention description in the first person.

Table 12 – Illustration of the development of the seven stage intervention

	Stage 1	Stage 2	Stage 3	Stage 4	Stage 5	Stage 6	Stage 7
Purpose	Listen to the narrative	Identify the Problems	Give targeted information	Explore realistic options and assist in decision making	Support the decisions made	Provide strategies to maintain the condition in the workplace	Facilitate a positive withdrawal from the workplace
Narrative	*"I can't do my job and I have to leave"*	*"I can't explain why I need to leave"*	*"I don't know what information I need or how to get it"*	*"I have options, but what is best one for me?"*	*"I know what I want to do but how do I take this forward?"*	*"I can cope at the moment, but how do I maintain this?"*	*"I am leaving work, what next?"*
Themes	How many R are still working? When did R leave work? On what basis did they leave?	Why did R leave work?	What do R see as the benefits of staying in work? Where have R looked for information? R knowledge of employment rights	Factors that influences R decision making Impact of maintaining work on other aspects of life R reflections on having left work	Factors affecting R decision to disclose Experiences of disclosing Employers' reaction to the disclosure Sources of support Alternative work roles and options Financial issues	Altering tasks in the workplace Environmental design and equipment Fatigue and anxiety management Dealing with employers Coping with a changing condition	The effects of PD on leisure activities The effects of maintaining work on leisure activities Activities adopted following withdrawal from work
Literature	Number of PWP in employment. When PWP left work	Symptoms of PD that may impact on ability to work	Benefits of working Legislation Sources of support in employment	Symptoms that may be exacerbated by leaving work or staying in work	Symptoms that may make disclosing difficult Statutory support available for supporting employment	Impact of non motor symptoms on work	Adaptation to job loss Social withdrawal Benefits of exercise for PWP
Intervention	Gather employment history Understand what work means to them Establish an identity as a person and not a patient	Identify specific symptoms and their impact on the job role De-personalise and enable the PWP to look objectively at specific difficulties	Educate regarding employment rights Reinforce benefits of staying in work Advise to retain current job and contract	Establish why the PWP needs to work Identify job role requirements Visualise a goal Identify time frame	Creation of an action plan Advise informing employer of diagnosis Identify sources of support Consider options for adapting job role	Provide advocacy Support disclosure Teach strategies to maintain the condition in the workplace	Facilitate constructive adaptation to withdrawal from work Create a plan of withdrawal Develop beneficial activities to replace employment Transfer coping strategies
Change of narrative	*"I have a career and I also have PD"*	*"These are the symptoms of PD which are causing me difficulty in my work"*	*"I know what my employment rights are and I understand the options open to me"*	*"I have weighed up the options and have made a positive decision to stay in work"*	*"I know what I need to do in order to stay in work"*	*"I have strategies that will enable me to remain in work and respond to changes in my condition now and in the future"*	*"I am making an informed choice to leave work and have a range of beneficial leisure activities to engage in"*

Respondents in the study are referred to as 'R'. People with PD are referred to as PWP.

6.2 Intervention Stage One

Purpose of Stage One - Listen to the narrative

6.2.1 Clinical Reflection

When I initially started working with younger people with PD I was struck by how readily this client group was willing to give up their employment. Occasionally, people actually wanted help to retain their job, but generally, when people were referred to me, in their first appointment they wanted me to reinforce why they were unable to stay in work. Either way, in almost all cases the rhetoric was negative and defeatist, typically:

'I have to give up…I can't stay at work in this state …there's nothing that can be done.'

The individuals were creating narratives validating why they were leaving work, trying to convince others and themselves that there was no solution other than to leave work. Therefore this stage of the intervention was developed from a need to listen to the person with PD describing their thinking regarding employment, and, establishing a picture of their current employment situation.

Narrative at the beginning of Stage One – '*I can't do my job and I have to leave'*.

6.2.2 Themes arising from the data

How many people in the study were working?

The results gathered in the three data collection methods indicate that retaining employment is an issue for people with PD. The questionnaire highlighted that the mean age of respondents was 51 and only 38% of respondents were still working. In the focus groups less than 50% of people remained in work and in the stories 60% of respondents were working with a mean age of 51. The discrepancy between the number of people in the questionnaire and the number of people in the stories remaining in employment was probably due to the source of respondents. The majority of questionnaire respondents were sourced via the PDNS network and the story respondents came via a web-site that specifically targeted people with PD who were in employment.

When did they leave?

The average age that the questionnaire respondents left their employment was 48 (ranging from 30 to 59) and they stated that if they had not been diagnosed with PD they intended to leave work at the normal age of retirement, therefore the average number of years lost in employment for this group was 13.5 (taking into account that the normal retirement age of women being 60 and for men 65). In the stories people left 13 years prior to their normal retirement age, a very similar result to the questionnaires.

There was a wide range of responses in the questionnaire when asked *'How long following diagnosis did you leave work?'* Responses ranged from 1 to 168 months with the mean length of time being 3.6 years. Although specific data was not taken, this range was echoed in the focus groups. In the stories, the mean time between diagnosis and leaving work was 36 months, again reinforcing the results of the questionnaire and, highlighting that people did not maintain their employment for very long following their diagnosis.

On what basis did they leave?

In the results of the questionnaire, the majority of people who left work due to PD either took early retirement (44%), or were retired on the grounds of ill-health (34%), this information was not collected in the stories or focus groups specifically but the responses in the focus groups indicate that they usually took redundancy if offered or ill health retirement. A theme that came out of the focus groups was that often people 'jumped' rather than waiting to be pushed taking up the offer of early retirement or redundancy, stating that they felt as if they would be 'sacked' due to being unable to carry out their job. This thought again validates the narrative for leaving.

Justification for leaving - negative
"I had a good offer…they were getting rid of people …I would have to leave eventually anyway" (FG1R3)
"I could see myself being made redundant if I didn't retire…" (FG3R6)
"I filed a sick note and down came the redundancy package the way things of turned out the way I feel with the Parkinson's I couldn't have coped with the new job and   there was no support if I had of carried on so I took the redundancy package but I have left on a reduced pension." (FG2R3)

> *"The time was right I was ready to leave, company at the time was downsizing you know they didn't ask me to leave."* (FG2R4)

However, some people acknowledged that they had taken the easy way out or felt positive about their exit and justified that they had more to do in their lives than just work.

Justification for leaving - positive
"I thought it might be time to go I was head librarian and managed 6 people which was stressful in its self I'd rather enjoy myself now and travel, do all the things I want to do. I have an active life outside of work and as a woman I have a man to support me so I took the easy option and left and for me it was an easy option and I was glad to be retired." (FG3R6)

A large number of respondents described leaving work due to a lack of flexibility from their employer, medical requirements of the job and feeling like they were a burden to their colleagues. However, the respondents did not describe challenging this 'push' out of employment.

Reasons for leaving
"You can only rely on other people for so long can't you?" (FG3R6)
"I was a self -employed heavy goods driver I carried on for 3 yrs and I decided to pack it in because I didn't feel safe." (FG3R11)
"I was 'slow' in using my keyboard. Unfortunately my line manager sits opposite and would stare at me or worse still make comments." (S8)
"I had been in this post about four years My position required 150% dedication and it was obvious that I could not be carried." (S19)
"Initially I took sick leave to get my head together. It wasn't the physical factors more the emotional impact. When I did return I was sent to Occupational Health on the morning of my return and a doctor who didn't meet me banned me from driving during working hours!" (S8)
"I was off for about 6 months and they sent for me at the Occupational Health and they said you can't work with what you've got and that was it." (FG2R3)

6.2.3 What does the literature say?

Examining the literature to identify the number of people with PD remaining in work or leaving work due to their PD reveals a range of results. However, a closer inspection shows that often the information is retrospective and is gathered from people who are beyond normal retirement age and who may have been diagnosed with PD following retirement. The information published in the PDS member survey of 2008 states that 17% of people gave up work due to their PD (PDS 2008) but does not indicate how many people of working age remained in employment. In the PDS member survey of 1998, 23.4% of people under 65 were still in employment (PDS 1998). A later PDS survey specifically targeting younger people found 47% of respondents of working age remaining in employment (PDS 2002). Banks and Lawrence (2006) discovered that 30.4 % of people of working age remained in employment. The questionnaire results sit within the range produced by the literature, confirming the nature of the problem in that only 23.4% to 47% of younger people with PD remain in employment.

6.2.4 Stage One Intervention

To begin with it is useful to create a clear employment history to this point asking the individual about their employment history, how long they have worked in that position, the nature of their contract etc. This encourages a positive narrative, focusing on employment rather than on PD. Usually when speaking to any medical professional the focus is around their deteriorating condition, not on their abilities, so it can be a rather different experience to talk about themselves as a person and not a patient. Facilitating this employment narrative is necessary to make sense of the notion of a 'self' (Dunne 1996) and helping the individual to make sense of their lives through this story, if the narrative about employment is negative or incomplete then they may fail to make sense of what is happening to them.

The individual is then guided to talk about what work means to them. This is a natural progression in the interview, discovering if their job is a vocation, an identity, a way of making a living, a way of supporting the family, or a social outlet. This is a crucial aspect of the intervention, establishing the importance of work in the life of the person with PD and enables the person to talk positively about their experience of work and the position it has amongst their other life roles, activities and occupations. Viewing work

as a method of productivity alone is, for many people, reductionist, the experience of working being more important than its label.

So by the end of Stage One of the intervention, I have gathered an employment history and the nature of their current post and contract. Alongside this factual information, I have drawn out the meaning of work to the individual and began to understand what will be lost if he/she leaves employment i.e. what impact a loss of employment will have on the individual. My understanding of the situation is established, and from the onset of this intervention I can, regardless of what the end result might be, begin to therapeutically re-frame the narrative by introducing the concept of choice and control.

Moving on from Stage One of the intervention to Stage Two, the questions that I am usually considering, and that help to shape the following stages of the intervention, are:

- Does the individual really feel that only one option is open to them? i.e. leave work, or is it lack of information about options available?

- Has PD decreased the individual's confidence to such an extent that they believe they are unable to competently contribute to the workforce?

- Are external drivers pushing them out of work? Or are the cognitive symptoms associated with PD making them unable to problem solve?

<u>Summary of Stage One Intervention</u>

- Gather employment history.

- Understand what employment means to the individual

- Establish an identity as a person and not a patient

> At the end of Stage One the narrative should have moved from:
>
> *"I can't do my job and I have to leave"* to *"I have a career and I also have Parkinson's."*

6.3 Intervention Stage Two

6.3.1 Clinical Reflection

This part of the intervention was developed when I recognised that people with PD were unable to articulate what difficulties they were experiencing. This was a common factor to almost all people with PD who were referred to me for intervention regarding employment issues. They were rarely able to tell me what specifically the reasons were for leaving work, tending instead to voice a defeatist and yet adamant statement of:

'I've got Parkinson's, I can't stay in work'

When I began to deconstruct the narrative of 'having' to leave work there seemed to be two major factors underpinning it. Firstly that people expressed a strong 'push' force out of employment that appeared to be of external influence and secondly that they had little sense of control over this situation.

This stage of the intervention was created to enable the person with PD to identify the specific reasons why they feel they needed to leave work and to begin to develop a sense of control around these reasons.

Narrative at the beginning of Stage Two: *"I can't explain why I need to leave."*

6.3.2 Themes arising from the data

Why did people leave work?

Of the questionnaire respondents who were currently unemployed, 92% of them left work due to PD. For most respondents the reasons for giving up work were complex and numerous. A free text response was indicated for this question and the majority of respondents who answered this question gave more than one response citing both symptom orientated reasons and the attitudes or medical requirements of their employers. However, almost half of the respondents did not give an answer to this question perhaps indicating that they had difficulty in formulating an answer.

When considering symptoms, 45% of questionnaire respondents cited physical symptoms and these were identified as being; freezing, tremor and fatigue. In addition, 23% stated psychological reasons and these were identified as being; anxiety,

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depression and stress. Only one person identified psychological factors alone being the reason why they gave up work.

Within the focus groups, participants echoed the results of the questionnaire but with the added enhancement of explaining why, and how, these symptoms impaired their ability to work. Fatigue was identified by many respondents as being their major impairment to employment.

Fatigue
"[name] gave up his job because he would literally be stood up asleep from work." (FG3R11W)
"...by the time I got home I was cream crackered and my home life was going down the drain. I was just exhausted, that was mainly the reason why I left in the end." (FG2R4)
"...I just couldn't maintain the stamina for the things needed to be done." (FG3R1)
"You got so tired trying to do the job you couldn't do it, so my employer's then took me in hand and said enough is enough." (FG3R3)
"I was finding long journeys difficult and allowed journey time to nap in a service station." (S10)

Some participants mentioned the impact that the typically monotonous voice associated with PD has had on their employment roles.

Changes to speech
"I tend to say very little at all and if I do someone else tends to repeat what I say for me. For me one of the main symptoms is my voice..." (FG1R2)
"Can you see one common denomination in the group? People with Parkinson's have to try a great deal to make the voice go up..." (FG2R4).
"... it's the voice because you sound sort of bored less enthusiastic." (FG2R2)
"After a long day, I could hardly speak." (S20)

Respondents also highlighted the impact that reduced dexterity had on their work, particularly if their work involved keyboard use or hand writing.

Reduced dexterity
"… little things like trying to get things done at the end of the day putting papers in envelopes I was finding that difficult…" (FG1R1) *"I can't work on the computer as I can't push the buttons anymore which makes me very frustrated at times."* (FG1R3) *"I realised that I was making typing mistakes and my handwriting, when taking telephone messages, was getting smaller and smaller."* (S19) *"My writing became very small. Having to use the computer, if I accidentally allowed my hands to rest over the keyboard whilst composing my letters etc, I would end up with a line of //// or aaa's!"* (S18) *"Slowness in my left hand affected my computer keyboard skills. I keep holding keys down longer than I should and the co-ordination between left and right hand is difficult."* (S5) *"Inability to shuffle paper ie, letter filing, sorting through reports, no longer dexterous. Parkinson's affects my left side. Later I found it difficult to use both hands when using computer."* (S6) *"I started to feel that I was not able to do certain tasks that were fiddly or when I was being watched doing a particular skill that required dexterity - infants shirt buttons, threading needles, doing up unruly shoe laces, etc. this was probably about three years ago but more noticeable to me than others."* (S15)

Posture and positioning was an issue for some people, although as a major symptom of PD this was not highlighted by as many respondents as would be expected.

Posture
"Sitting for a long while also used to make me very stiff and uncomfortable. Probably the most stressful was the continual pain in my right shoulder." (S18) *"By the end of the day I had pains in the back of my neck."* (S20)

In two of the focus groups, and in the stories, the issue of cognitive changes was raised, which hadn't been identified by respondents in the questionnaires.

Cognitive changes
"I would have had to change job or location for work, I think I would have found it frustrating that the people under me would have expected me to work and think quicker …" (FG1R1)   *"… you feel though that your credibility was reduced by the end because of your symptoms. I feel cognitively you change as well I think some of my cognitive stuff has gone too".* (FG3R8)   *"Unable to, concentrate and carry out client interviews, memory loss and confusion also impacted on my ability to carry out my duties."* (S1)   *"Initially PD had little effect although concentration was becoming more difficult."* (S11)   *"I find it hard to focus on things to complete them."* (S4)   *"… memory, concentration and social skills all suffered."* (S1)

The psychological factors identified by the focus groups were mainly stress related. A reduced ability to cope with stress, which respondents felt affected their motor symptoms, seemed to be compounded when dealing with the public or being expected to be 'on show'. Respondents also described a decrease in confidence combined with the unpredictability of the condition and how anxiety affected other areas of their life.

Stress and anxiety
"You would get yourself worked up for it getting into the classroom, when you've got Parkinson's you can't cope with it." (FG2R1).   "*…when customers get irate I was one of the one's who had to pacify them, I would sense the tremor coming on…in front of important customers there would have been no support there and the customers, they want a service, they would have had no sympathy that I have an illness*". *(FG1R1)*   *"I don't think I would impress a client stood at his door shaking like a leaf…"* (FG1R3)   *"The confidence is lost… with strangers especially".* (FG2R4)   *"I found difficulty speaking when stressed or tired. Clients were puzzled. My 2 business partners panicked."* (S20)   *"A tremor which gets worse the more anxious I get."* (S3)   *"Somewhere in or about 1998 depression and panic attacks were very severe.* (S1)   *"…also the stress of keeping yourself going that spills over into the evening when you continue to be stressed and anxious."* (FG3R1)

Respondents also described the effect of having difficulty to negotiate around their work space.

Moving in restricted space
"I was then having difficulty moving around the reception area without getting in other peoples way". (S6)

The symptoms which impacted on work that were identified by respondents in all the data sources were;

- fatigue,

- monotonous and quiet voice,

- dexterity particularly when writing or typing,

- mobility and balance particularly within confined spaces,

- cognitive changes particularly memory and slowness of thinking,

- stress and anxiety, which exacerbates the physical symptoms and causes a lack of confidence when being observed or having to face people.

All respondents identified a range of symptoms, however there were some noticeable differences between both the detail given by the respondents and the types of symptoms described by them. Greater detail, which indicated a high level of awareness of symptoms, was given by respondents from the stories rather than in the questionnaire or focus groups. This is perhaps explained by the age difference between these groups, the story respondents were younger than questionnaire respondents. The questionnaire respondents did not identify any cognitive symptoms and a large number of questionnaire respondents were unable to identify the symptoms or reasons that caused them to leave work.

6.3.3 *What does the literature say?*

The literature was examined for evidence to validate the list of symptoms which respondents identified as impairing their ability to work. Literature tends to define Young Onset Parkinson's Disease (YOPD) as being onset at age 21 to 40 (Quinn et al

1987) and older onset or Lewy Body Parkinson's as onset over 40 years which indicates two sub-types of PD, the earlier onset being predominantly a motor disorder and the later onset associated with greater mental deterioration (Schrag et al 1998). However, in the study it is interesting to note that the younger participants who responded to the on-line story request were more aware of cognitive effects than the slightly older group who responded to the questionnaires. An alternative justification for this has been argued by some researchers claiming that differences between younger and older onset are explained by physiological changes or age related factors that are unrelated to the disease itself (Pantelatos and Fornadi 1993). The cardinal features of PD include slowness of movement (bradykinesia), poverty of movement (hypokinesia), rigidity and rest tremor. The predominant motor disorder of YOPD includes motor fluctuations (particularly in response to L-dopa) and a significantly higher rate of abnormal voluntary movements or dyskinesias occurring frequently and, early, in the course of the condition (Pantelatos and Fornadi 1993, Schrag et al 1998). It was surprising that none of the respondents in the study identified dyskinaesia as a symptom that impacted on their work, however this could be due to people leaving work prior to the onset of this feature.

PD has a wide-range of non-motor symptoms associated with it, which are becoming more widely recognized by health professionals. The most common ones being depression, cognitive impairment, psychosis, anxiety, fatigue and sleep disorders. In the study respondents reported all these symptoms other than the psychosis, which is more prevalent in older people. It is estimated that these symptoms occur in between one third and half of all patients with PD (Shulman et al 2002, Kostic et al 1994). Studies suggest that depression may in fact be the first symptom that is presented in PD (Shulman et al 2002), emerging before the motor symptoms and may actually be an indicator or marker of PD (Shiba et al 2000). Younger people who tend to have lower disability scores than older patients, have been found to have higher rates of depression (Starkstein et al 1989, Jenkinson et al, 1999), perhaps indicating their higher expectation of function than an older person or due to problems of adjustment (Jenkinson et al, 1999). However, in relation to depression and impairment of activities (Kostic et al 1994), the 'cause and effect' is still open to debate. If depression in PD does not have a neuro-chemical basis, are activities impaired due to the symptom of depression or are people with PD depressed because of their reduced function?

Anxiety has been found by some researchers to occur in a higher percentage of people with PD than depression, accounting for over one third of people with this condition (Jones et al 1999). Anxiety in people with PD has been linked to their fears about managing the condition, in addition to fears about physical deterioration in the future (Lloyd 1999). As both anxiety and depression are often experienced during the early stages of the condition by people of working age, they could contribute to both the ability to engage in employment, and, the ability to develop coping strategies to manage the physical and social symptoms which may impact on employment.

Additional non-motor symptoms include sleep disorders and fatigue. People report that their sleep pattern has been reversed i.e. sleeping during the day and remaining awake at night. Many report falling asleep in the early evening and waking in the early hours of the morning. Fatigue in some cases is of course linked to insomnia but in other cases it would appear to be unrelated to a lack of sleep and linked to the increased cognitive and physical effort involved in performing everyday activities, or is associated with the 'off' state (Witjas 2002), and fatigue was certainly a major symptom acknowledged and recognised by the respondents in the study.

As described in Chapter 2, apathy has recently come to be associated with PD and is now considered to be a symptom in its own right. One study estimated the prevalence in the PD population as being between 16.5% and 42% (Pluck & Brown 2002) so it is surprising that it was not acknowledged by any of the respondents. However, although not specifically articulated in the study, the features of apathy were alluded to by respondents in their range of symptoms. As apathy could be termed as a socially unacceptable symptom and has only recently been recognized as a symptom of PD it is unlikely that the respondents would acknowledge it or report it. Indeed, perhaps apathy was one of the symptoms that contributed to a withdrawal from employment for those respondents who were unable to identify their reasons. In relation to employment, the most interesting results in the Pluck and Brown (2002) study concerned the relation between apathy and cognition, people with high apathy levels performed below the level of those with low apathy on various measures of executive function. These difficulties associated with executive function or cognition included disordered thought and memory, again, although not specifically mentioned in the study, were alluded to when respondents were describing the impact of PD on their cognition.

Although not a symptom in the traditional sense, the social impact of PD is considerable and seems to differ from that of other progressive disorders. When socialising, people

with PD report that they feel inclined to retreat from social situations due to their embarrassment in situations in which they are required to walk, talk or eat (Nijhof 1995, Reese 1999). PD has been associated with feelings of shame and stigma and a perceived lack of social competence. A Dutch survey indicated that one in four people reported feeling embarrassed by their illness (de Boer et al, 1999), whilst a British survey found that 42% of people felt embarrassment due to their PD with 48% of them reporting a need to avoid public situations (Peto, Fitzpatrick & Jenkinson, 1997). In the study respondents identified the additional stress they felt when dealing with their symptoms in public, the need to avoid being 'on show' and wanting to withdraw from roles where they had to deal with customers or make presentations.

6.3.4 Stage Two Intervention

The key outcome of this stage is to create a list of the problems experienced and identify how they impact on the individual's ability to carry out their employment role. In doing this in a symptom orientated way, it begins to depersonalise the situation and enables the person with PD to focus on the symptoms and other difficulties encountered from a stance of detachment. This process requires some time, as it has been identified in the study that it is often difficult for the individual to identify the specific symptoms that are impacting on their employment. Knowledge of the symptomatology of PD is essential in this process as I gently, but resolutely, direct questions to enable both myself and the individual to discover why they are unable to carry out certain tasks within their employment role. It has often surprised me that people with PD don't assign a symptom to the inability to do a particular task, and then seem astonished when they realise that it is not 'them' unable to do the job, but an actual symptom of the condition that is affecting their ability to do the job. So, an important outcome of this stage is that the individuals' difficulties are validated in this way, particularly some of the 'hidden' symptoms e.g. the cognitive or psychosocial symptoms such as cognitive inflexibility, apathy, depression or anxiety.

By the end of Stage Two of the intervention I have established a list of symptoms that are impacting on the individual's employment. In addition I am beginning to pick out what impact withdrawing from this employment might have on the individual, and I continue to re-frame the narrative by moving from a personal account of incapacity to an impartial symptom list.

Moving on from Stage Two of the intervention to Stage Three, the questions that I am usually considering and that help to shape the following stages of the intervention are:

- What are the symptoms that are impacting on the individual's employment roles?

- Is the individual receiving optimum symptom management?

- Are there any Health and Safety implications of the impact of the symptoms on the individual's ability to carry out their employment role?

- Does the employer know about the diagnosis?

- What information does the individual require at this stage to assist them in their decision making?

Summary of Stage Two Intervention

- Identify specific symptoms and their impact on the job role

- De-personalise and enable the person with PD to look objectively at specific difficulties

> At the end of Stage Two the intervention moves the narrative from:
>
> *"I cant explain why I need to leave"* to *"These are the symptoms of Parkinson's which are causing me difficulty in my work"*.

6.4 Intervention Stage Three

Purpose of Stage Three - Give targeted information.

6.4.1 Clinical Reflection

This part of the intervention was developed when I discovered, during my clinical practice, how little people with PD knew about remaining in employment with their condition. I was surprised in some respects as there is an incredible amount of information 'out there' either available from the PDS, on the internet or from statutory welfare or employment services. However, what people seemed to be struggling with, was extrapolating the information relevant to their own situation, such as how their symptoms might affect them at work, what rights they had, what support is available and if for them, would remaining in employment be detrimental or therapeutic? People with PD who were referred to me did not know what to ask me or where to start. Following the narrative established in Stage One and Two, people felt there was no option other than to leave work, so moving on from that concept often left them floundering for information. They wanted me to give them information relevant and specific to their own situation and lifestyle.

I also discovered that many people with PD who I was involved with who had already relinquished their employment often spoke with regret about leaving work, and described the negative effect that the loss of employment had on their lifestyle and their condition. From the viewpoint of a therapist, I already knew that many aspects of work were beneficial to symptom management in PD. Therefore I wanted to find out from the data if people with PD felt work was beneficial and if so, why? I could then pass on this information, which would be a key message, to people with PD referred to me. I also needed to find out what other information people thought was useful during their decision making, or in retrospect wished they had known and if they had received information, where it had come from.

The outcome of this part of the intervention would be specific and targeted information given to each person with PD.

Narrative at the beginning of Stage Three – *"I don't know what information I need or how to get it."*

6.4.2 Themes arising from the data

The respondents' opinions of employment were gathered from the data. Firstly data relating to opinions or reasons regarding the benefits of remaining in work and secondly data is investigated to discover what information the respondents found useful, what they required and if they had received any information regarding employment, where they had got it from.

What did the respondents think about remaining in employment?

The majority (75%) of the questionnaire respondents thought that it was beneficial to remain in work. The most commonly identified benefits were working for financial recompense (36.7%) and of equal importance to the same number of respondents, working to maintain self-esteem/confidence/wellbeing/self-worth (36.7%). Other popular reasons included working for social contact (26.7%) and as a way of making a contribution to society (20%). Respondents also listed mental stimulation (16.7%), distraction from condition and structure to the day (16.7%), physical fitness (15%) and promotion of their condition (5%).

Overall the reasons given by the focus group and story respondents were similar to those from the questionnaire with the only difference being that financial recompense was not given as the primary benefit by the majority of participants, although was still a notable aspect.

Financial reasons
"Staying [in work] *because like anyone I need the money."* (S8)
"Financial need - I earn a good salary and we have a lifestyle to match, which may change dramatically if I finish work." (S5)
"I needed to keep working to pay the mortgage." (S20)
"[if left work]*I would be unable to afford leisure activities or to buy things for my garden; a crucial part of my survival both physically and mentally!"* (S2)
"If I left it [work] *would curtail certain freedom with leisure activities such as an annual holiday, spending money on the garden which I love. Not spoiling the grandson, or indeed helping the children out generally."* (S15)

Respondents who had given up work acknowledged missing social contact when they left work and how important that contact was to them.

Missing social contact
"I think you realise for the first it's like a wedding for the first 3 months it's fine but then you miss the conversation miss all that sort of thing, what you watched on T.V. last night etc." (FG1P1) *"...all your friends are working."* (FG1P1W) *"You suddenly don't see the people who you talk to all day long, you are no longer there."* (FG2R2) *"Disappointed* [when gave up work] *in as much as I enjoyed the camaraderie of the office and of the clients."* (S11) *"I want to keep active and socialising."* (S13) *"It is nice to be retired but you do miss the interaction with people there no substitute with that."* (FG3R10)

Respondents identified the sense of satisfaction they got from working and placed considerable importance on it. The need to continue to develop their career was highlighted by the respondents and they resented the impact that PD could or did have on their career. Respondents reflected on their employment giving them a sense of identify which was lost when they relinquished their employment.

Satisfaction, identity self-esteem and career
"Yes the kids I love maths a light comes on in someone's face when they understand, teaching can be the best job in the world. I do miss it." (FG3R1) *"I love my job. I wouldn't like to give something up that gives me so much job satisfaction."* (S3) *"...I also want to develop my career. Having Parkinson's doesn't change your aspirations or needs."* (S8) *"Torn* [when deciding whether to leave work] *because I loved my work and much of my identity was tied up in my career".* (S12) *"Difficult to just be housewife again. Needed to boost my own moral, felt a little useless. Not needed, had to find identity again."* (S6)

> *"I'm coming to grips with this* [leaving work] *right now. I am having to redefine myself."* (S12)
>
> *"Teaching was me I was teaching, rightly or wrongly it became me, and therefore I was no longer that me anymore."* (FG3R1)

The need for mental stimulation was identified as an important aspect of work for the respondents.

Mental stimulation
"My condition at present is fairly mild and particularly as I live alone I feel that working keeps my brain going." (S10)
"I would need to have plenty to do to keep me active, mentally . I lead a busy life. If and when I finish work that may be a problem." (S5)
"I needed to keep working …to avoid becoming terminally bored." (S20)
"I like my job. My G.P. advises me to carry on as it is a therapy in itself." (S15)

Obviously there were some negative aspects related to remaining in employment given by the respondents, however they are not presented in this stage but are utilised in Stage Four of the intervention.

Where was information sought?

Just over half of the questionnaire respondents (55%) did not receive any assistance/information to remain in employment and 58% of respondents did not even seek assistance/information. However, the people who sought assistance/information looked for it in a variety of settings, with their employer/HR being approached by the most respondents who sought help (25%), followed by the PDS (16.7%) and the Job Centre (12.5%).

In the focus groups and stories it would seem that a higher number of participants sought and received assistance than the respondents to the questionnaires, and identified a wider variety of sources of information.

Sources of information relating to employment
"…when I came off sick last year, I went to the P.D.S. to see if there was anyway that I could get anything that would help me maintain the lifestyle and they sent me loads and loads of information and I got no further and ended up back at work it was all gobblygook." (FG1P4) *"My PDNS, my GP and my Occy Health counsellor have supported me, listened to me, wiped my tears and generally "been there" when I needed them. Job Centre Plus are amazing."* (S3) *"Employment departments are not always helpful, and try to offer menial jobs. Just because I wanted less hours, did not necessarily mean that I was not capable of doing my job properly. The support I have with my present employer is excellent. I have tried to get help with DLA in order to reduce my working week, but that attempt was unsuccessful."* (S18) *"I went to see the Disability Employment Adviser at my local job centre."* (S17) *"I have the PDS employment information."* (S3)

However, sometimes these participants tended to describe general sources of support, rather than sources of information relating to employment.

General sources of information
"I contacted the local P.D. community support, who also suggested that I contact the P.D. Nurse for this area." (S15) *"PDS loads of help from my local branch."* (S17) *"Friends with PD I have made since my diagnosis have been very helpful in steering me towards the kind of things that may be available and sources of help."* (S5) *"My GP and PD Specialist nurse have been brilliant as has the consultant and local Occupational Therapy lady."* (S7) *"PDS Helpline were wonderful."* (S14)

One of the key areas of information relating to employment for someone with any illness or disability is knowledge of welfare rights. In this study, a specific question was not asked about this in the questionnaires, but as the importance of this knowledge was highlighted by the focus groups participants, it was subsequently included as a particular area of investigation in the final data collection method. Some of the assumptions that respondents had regarding their rights was incorrect, and others

described the difficulty they experienced when trying to implement their rights whilst having this condition.

Knowledge of welfare rights
"There are some laws aren't there to protect the disabled?" (FG1P2)
"I have good knowledge of my employment rights. However, if I become more incapacitated, I think I will find it difficult to 'work the system'." (S2)
"PDS Welfare Rights Officer. My husband and I attended a Welfare Rights day in Manchester. He gave us advice about claiming disability allowance. He followed this up on the telephone." (S8)
"I have some knowledge, based on guidance from the Parkinson's Disease Society." (S5)
"Only that they can't sack you for having PD." (S7)
"Enhanced through attending PDS awareness day in Manchester. Also through internet use Disability Discrimination Site." (S8)
"Little except to say that I was aware that they should not discriminate against me." (S10)
"I think I have a pretty good grasp of my rights. In order to fire me the district would have shown over a period of time that I couldn't do my job. They would have needed to adjust my working situation as it became necessary." (S12)
"I know a bit as I sent for an employment pack from the PDS." (S13)
"I knew somehow that Employers are obliged to employ a certain percent of 'disabled' staff however broadly the term is defined. I also know that unless I do something drastically wrong there would no real grounds for requiring a resignation from me. I would offer my resignation if I felt that there was the slightest way I was not fulfilling my role properly at school." (S15)

Financial considerations have been identified by the participants as one of the main factors in the decision making regarding remaining in or leaving work, and are therefore a key information need. Retrospectively some participants identified regrets surrounding what they should have done regarding their finances.

Finances
"We went straight to [Welfare Rights Adviser] at the Parkinson's Disease Society. We had had various conversations with him at open days and decided this was the time to talk to him and to be quite honest he wasn't that much help, we wanted specifics on how to get the best package possible as we have a young family… I don't feel that that type of advice is out there and I feel

that wherever you go people tell you your entitled to this or to that and if you do that there are two options that this might happen or this there again this might happen but for us we can't take that risk because if we end up with too little money then it's the kids that suffer and so we keep quiet and just keep plodding on because there's no-one out there who says let's have a look at what you have got and look at the ways forward it's a minefield." (FG1P2)

"I should have gone on the sick before I was made redundant and I probably would have got my pension as if I had worked till I was 62." (S17)

"I made all my decisions based on information available to me at the time. If I could go back it would be to get a more accurate prognosis of my financial state." (S1)

"But if you have any kind of pension it's there you lose it of your pension, your incapacity you can only have a certain amount, you start losing it." (FG1P4W)

"Well I met the PDS Welfare Rights Officer on one of the Bradford nights and he said yes I had a case to get my pension made up and he could do it, I wrote to him and about three months later it concluded that I had left it too late." (FG1P1)

"We don't know if any benefits will have a knock on effect to children's tax credit and by how much, we don't know because until you say that we are actually going to do it they will not say how much. I find that really, really hard because it is so unsure. The pensions are a black area at the moment they don't look on the positive side only negative side, and at your age the pension has to last a long time." (FG1P1W)

6.4.3 *What does the literature say?*

These key areas of information need that were highlighted by the participants were examined in the available literature:

- The benefits of working

- Legislation

- Sources of support in employment

Benefits of working

For most people their workplace is a social situation with the majority of daily social contacts occurring within the workplace. Withdrawing from this workplace can severely reduce the person's social network. This is a particular problem for people with PD as wider social networks have been observed to also suffer in that they tend to be ever

decreasing across the duration of the condition (Schrag, Jahanshahi & Quinn, 2000). This impacts not only on the individual, but increases the pressure on close family relationships, which feel the strain of coping with PD in isolation (Jenkinson et al, 1999). The loss of social contact after leaving employment is an added complication for those who live alone. A survey found that one in five people with PD lived alone and reported feeling isolated, with lack of social contact being the most common non-medical problem they expressed (Oxtoby, 1982).

The effect of a lack of employment on people with disabilities has been recognized by various government bodies. The inspection of Welfare to Work for disabled people acknowledged the importance of employment for disabled people "in terms of self-fulfillment, income and interactions in society" (SSI 2001). However, it is not only psychologically beneficial, as it has been found that employed people are less likely to report health problems than those who are unemployed (Steward 1996). In a review of the evidence surrounding work, health and well being commissioned by the department for work and pensions came to the conclusion that work is good for health and well-being (Waddell and Burton 2006). They proposed a consensus around the reasons why sick or disabled people should remain in or return to work as soon as possible as work:

- is therapeutic;
- helps to promote recovery and rehabilitation;
- leads to better health outcomes;
- minimises the harmful physical, mental and social effects of long-term sickness absence;
- reduces the risk of long-term incapacity;
- promotes full participation in society, independence and human rights;
- reduces poverty;
- improves quality of life and well-being (Waddell and Burton 2006).

It should be highlighted that the majority of the work in their study is based on 'common health problems' such as mild/moderate mental health, musculoskeletal and cardio-respiratory conditions and not a progressive degenerative condition which raises its own unique problems. However, although articulated differently, the majority of the reasons identified by Waddell and Burton (2006) were identified by the participants in this study.

Legislation

The employment provisions of the Disability Discrimination Act (1995) came into force at the end of 1996 introducing employment rights for people with disabilities. The Act makes it unlawful for all employers or potential employers (excepting the armed forces) to discriminate against somebody on grounds of disability. Under this act, employers now must make 'reasonable adjustments' to the working environment or role of an employee with a disability. However, the act does not describe what 'reasonable' is, and this is therefore open to interpretation.

For people in employment with PD this Act can protect them in so much as they can ask for 'reasonable adjustments' to be made to their job, however, as this an ill-defined acutance and employers can utilise Health and Safety Legislation, the individual would require a great deal of tenacity to implement the Act with a less than sympathetic employer. In 2006 the Disability Equality Duty (Disability Rights Commission 2006) was introduced, aimed at encouraging public employers to proactively target people with disabilities, however this Bill mainly focuses on the new employment of people with disabilities rather than encouraging the on-going employment of people already in work. Although there are legislative measures in place to protect employees with PD, a study funded by the PDS concluded that the legislation available protecting against discrimination in the workplace is insufficient (Banks and Lawrence 2006).

In addition, studies have shown that there is a lack of knowledge by people with PD about their rights. The PDS Younger Person's Survey in 2002 found that 67% of respondents would welcome information and advice from the PDS Welfare and Employment Rights Team and a more recent study funded by the PDS found that only 23% of respondents (of working age with PD) were aware of the Disability Discrimination Act (1995).

Sources of support in employment

There are established links between employment, health and social inclusion (SSI 2001), and with these motives (including financial security) in mind the government is aiming to increase the number of people with disabilities in the workforce.

Recent initiatives motivated by the established links between employment, health, social inclusion and financial security such as New Deal for Disabled People (DWP 2001), Pathways to Work (Welfare Reform Bill 2006), and the Condition Management Programme (A New Deal for Welfare – Empowering People to Work 2006)

acknowledged the importance of employment for disabled people as being not only related to income, but to self-fulfilment and interactions in society (SSI 2001).

This collection of legislature has attempted to challenge the attitudes of both employers and people with disabilities regarding employment and this is to help to achieve the government's targets of bringing the employment rate for disabled people in line with the general population. However, the Inspection of Welfare to Work (2001) report criticised a lack of multi-agency co-ordination of the services and the now familiar limited attention to employment by health agencies as part of rehabilitation. The various schemes and support programmes that can help people with disabilities to find or maintain work can be useful and relevant to those with PD but, as previously acknowledged, the lack of direction to these schemes leaves them underused by this group. The report also identified that there was little attention given to people with physical disabilities instead the schemes tended to focus on people with mental health problems or learning disabilities.

In July 2006 The Welfare Reform Bill (DWP 2006) was published and 'A New Deal for Welfare – Empowering People to Work' (2006) outlined a new initiative to move people from Incapacity Benefit back to work called 'Pathways to Work' which, following success in a handful of pilot sites, was rolled out across the country in 2008. 'Pathways to Work' is underpinned by the Condition Management Programme (CMP) which provides assessment and rehabilitation for people in receipt of Incapacity Benefit with the aim of enabling them to return to work. The CMP offers those on incapacity benefit support to understand their condition and its impact on their activities and help to regain confidence to be able to return to work (DWP 2006).

However this is an ambitious bill requiring legislation and different agencies to join forces and in regards to people with PD, this programme is limited in its usefulness as it focuses on those already out of work and in receipt of Incapacity Benefit, with the more common conditions such as musculo-skeletal disorders.

The British Society of Rehabilitation Medicine (BSRM) published a report (BSRM 2003) which identified unacceptable gaps that have arisen in the past 20 years between employment and health agencies in terms of the provision of rehabilitation services.

The main findings of the report state that there is a lack of understanding of the impact that disease and disability has on work and of the awareness of options to prevent people leaving work was noticeably lacking (BSRM 2003). The report highlights that

over the past two decades there has been a separation of employment and health services which has led to ignorance in the NHS regarding how to re-integrate people back to employment and that vocational rehabilitation is only considered after people have completed their 'health' rehabilitation. The report also criticises the lack of responsibility that the NHS takes in facilitating interagency working (BSRM 2003).

The report acknowledges that current government help is primarily targeted at people who are on incapacity benefit and that appropriately focused health care needs to be developed to prevent the progression of people with disabilities onto incapacity benefit. The report stresses that strategies used in job retention are proven to be valuable and are particularly effective within the first 3 months of sickness absence.

Moves towards the ideas expressed by the BSRM have started to be developed to support the implementation of Quality Requirement 6 (Vocational Rehabilitation) of the National Service Framework for Long Term Conditions (DoH 2005a). The BSRM are developing national guidelines on vocational rehabilitation for people with neurological conditions as part of the review of brain injury guidelines and at the time of writing (Jan 2009) are out for consultation. Again at the time of writing, a new white paper 'Raising Expectations and increasing support: reforming welfare for the future' (DWP 2010) describes intended changes to Job Centre Plus provision, however the implementation and the impact of these changes have yet to be observed.

So currently if someone with PD is struggling to maintain their employment and requires advice and support, the majority of statutory provision is not applicable. Ideally the first point of contact for someone with PD should be the local Job Centre, possibly not the most obvious choice for someone who is still in employment. However, the Job Centre can arrange an interview with the Disability Employment Adviser (DEA) who is an invaluable source of information for people who have difficulties at work due to a disability. However, often DEAS have limited knowledge of neurological conditions and their impact on employment and also are often unable to access and inability to access health professionals for this advice. The most useful scheme that can be utilized by people with PD who are in employment is The Access to Work Programme. It is particularly relevant to those with PD and can help by providing a range of assistance to overcome obstacles caused by disability such as a Support Worker, provision of adaptations to the work place and assistance with transport to and from work. Although the legislation and schemes are in place, there is an obvious need to support people with PD through the maze of legislation and towards appropriate assistance, where available.

A study funded by the PDS identified a serious deficiency in support for people with PD who want to retain their employment (Banks and Lawrence 2006) and that there was a need for targeted information and advice relating to employment for people with PD to enable them to make 'optimum decisions' regarding employment.

6.4.4 Stage Three Intervention

The key outcome at this stage of the intervention is to provide information that is specific to the individual's situation in order to then be able to consider the options available to him/her in the next stage of the intervention.

The initial information that I give almost universally is regarding employment rights, in particular the Disability Discrimination Act and I reassure the person with PD that he/she cannot be fired or forced to leave due to his/her condition. People with PD tend to react in two different ways to this information; either relief that they don't have to leave if they don't want to, or they portray a sense of almost disappointment that the decision to leave has been handed back to them rather than taken out of their hands *'..but I have to go'*. However, individuals have reported that this reassurance about their employment rights has given them more confidence when disclosing their condition to their employer.

At this point I move the discussion towards identifying the health benefits of remaining in employment. I inform the person with PD about the evidence base related to PD symptoms in general but do not allow the discussion to be hijacked into a detailed description of the individual's specific symptoms, which is dealt with in Stage Six of the intervention. Often this is the first time that anyone has spoken positively to them about staying in work. The majority of people with PD inform me that doctors, employers, colleagues, friends and family have told them to look forward to or even to be grateful for an early retirement. This part of the intervention again causes a sea-change for the individual's whole perception of themselves in relation to employment, they have rights and they could remain in employment if they choose as they are not a passive victim of circumstances.

At this point in the intervention the individual has been challenged with two new concepts in relation to their employment situation, so they need to go away and absorb the information they have received and think about how this may impact on their decision making. However the final facet of this intervention stage is to emphasise that

whilst the individual is in this decision making process, they should remain in work and retain their current contract, as it is easier to remain in work than to find a new job if they leave. At this stage I very briefly describe schemes such as Access to Work that may be able to offer very practical support to them, however specifics are returned to in Stage Six of the intervention. The individual is left at the end of this stage better informed, having received targeted information, but with a lot to think about.

Sometimes at this stage the person with PD exits from the intervention and does not attend further appointments. Having reflected on why this may be, I think that due to some of the non-motor symptoms such as fatigue and cognitive changes, some people prefer having the decision making regarding employment being made by someone else. Often, in my experience it is a decision that is reinforced by other health care professionals and perhaps well-meaning friends and family. However if the person decides to continue with the intervention, we move onto the next stage of considering realistic options.

Summary of Stage Three Intervention

- Educate regarding employment rights

- Reinforce benefits of staying in work

- Advise the individual to retain current job and contract

At the end of Stage Three of the intervention the person with PD has moved from,

"I don't know what information I need, or where to get it from," to *"I know what my employment rights are and I understand the options open to me."*

6.5 Intervention Stage Four

Purpose of Stage Four - Explore realistic options and assist in decision making.

6.5.1 Clinical Reflection

The key outcome in this stage is to explore the realistic options available to the individual with the intention of enabling him/her to decide which option to pursue. This stage was developed as part of the intervention when I realised how much assistance was actually required by the person with PD to not only source the relevant information but then to process that information to form possible options, and then finally to decide which is the best option taking into account the various influencing factors. The intervention needed at this stage from an occupational therapist with knowledge of both the symptomatic impact of PD and employment law and support schemes available is considerable. Often this is the first time that the person with PD has begun to understand that he/she has options so then trying to work out which option to take forward can be overwhelming.

I have seen the outcome of less informed decisions which people with PD later regret, such as giving up work completely and too soon or alternatively, retaining their employment to the detriment of social and leisure activities. A well considered decision will enable the individual to maintain activities that are important, enjoyable or necessary and essentially to not regret the decision later.

Narrative at the beginning of Stage Four - '*I have options but what is the best one for me?*'

6.5.2 Themes arising from the data

The collected data was examined to explore the factors involved when deciding to maintain or leave work. The results have been arranged into; the respondents' thoughts on maintaining or leaving work, the impact of maintaining work, their experiences of options such as part-time or self-employed working and finally reflections on having left work. These results could allow for a guiding framework of questions to be developed as a contribution to the intervention and in addition direct the therapist in the type of help this client group requires when maintaining work.

The respondents highlighted that they decided to leave when they felt that they had a range of issues or symptoms that were impacting on their ability to do their job, a sense that everything was becoming 'too much' to cope with.

Factors that influenced the decision to leave - thoughts about capability and symptoms such as fatigue
"Mine was an accumulation of thing, a series of incidents over the 12 months." (FG3R2)   *"I fell up the stairs twice, lurched about a bit, I felt down in the job not doing it properly, pride was an issue."* (FG3R3)   *"I was working full time then part time then finished. Your body just tells you enough is enough really, the safety aspect as well."* (FG3R6)   *"My inability to function and to carry out more than 15% of my normal workload. Mounting stress and a realisation of my limitations."* (S1)   *"The other thing as well is when you have Parkinson's you yourself don't know when your going to be off. It is different so... you can't predict...you just can't do it"* (FG3R8).

Issues regarding the work-life balance mainly focussed on fatigue. Due to employment the individual's did not have enough energy conserved to engage in activities outside of work such as being a parent to a satisfactory level.

Factors that influenced the decision to leave - thoughts about the work/life balance
"Fortunately we were not dependent upon my wage. I wanted to have some quality time at home before the disease progressed. Work was very stressful which wasn't good for my condition. I was tired!!" (S6)   *"My kids were very young and I was getting tired frequently."* (S9)   *"...I would rather spend the energy I had with my own children instead of coming home and falling into the couch, completely exhausted."* (S12)   *"...by the time I got home I was cream-crackered and my home life was going down the drain. The boys were barely school age. I was just exhausted, that was mainly the reason why I left in the end".* (FG2R4)   *"I knew that I could be a better father and husband if I retired."* (S12)

Respondents identified strong financial reasons for needing to stay in work. They acknowledged the importance that finances had on their QOL and some indicated that PD was causing them an additional financial cost.

Factors that influenced the decision to stay – thoughts about finances
"The money and pension. My consultant thinks I can work till 65 which was instrumental on my deciding to re-mortgage and build a garden room with downstairs bathroom attached. This has improved my quality of life immensely now and will enable me to stay in my home as long as possible." (S2)   "Financial need - I earn a good salary and we have a lifestyle to match, which may change dramatically if I finish work." (S5)   "Staying because like anyone I need the money." (S8)   "I would be unable to afford leisure activities or to buy things for my garden; a crucial part of my survival both physically and mentally!" (S2)   "If I left it would curtail certain freedom with leisure activities such as an annual holiday, spending money on the garden which I love. Not spoiling the grandson, or indeed helping the children out generally." (S15)   "I needed to keep working to pay the mortgage." (S20)

Respondents had realised that maintaining their employment was beneficial to them and that leaving employment would be detrimental to their well-being, particularly mental stimulation. Very few people identified that their employer had asked them to leave, rather, they had self-selected to leave. Perhaps this is linked to some of the non-motor symptoms of PD making them feel self-conscious, anxious or wanting to withdraw. Respondents to the questionnaires identified positive reasons for staying in work such as finances, social contact and self esteem, but also stated that work makes them feel 'normal' and gives a structure to the day, and stops them 'dwelling' on their condition.

Factors that influenced the decision to stay – thoughts about enjoying work, keeping active
[I need]… to avoid becoming terminally bored." (S20)   I would need to have plenty to do to keep me active. I lead a busy life. If and when I finish work, that may be a problem." (S5)   "I love my job. I wouldn't like to give something up that gives me so much job satisfaction." (S3)   "My condition at present is fairly mild and particularly as I live alone I feel that working keeps

> *my brain going."* (S10)
>
> *"I want to keep active and socializing."* (S13)
>
> *"I like my job. My G.P. advises me to carry on as it is a therapy in itself. I have just started going abroad for holidays and the pay comes in handy for that too!"* (S15)
>
> *"The tension is between difficulty being around wanting to teach and live but I want some money, because, but I don't want to shrink away and die, sorry that's too negative a view, but I don't want to disengage."* (FG3R5)

The respondents in the following table were all still in employment and they described the impact that fatigue had on their activities outside of work. This range of descriptions were very similar to those identified by respondents in a previous table who were describing why they left work, indicating that fatigue is one of the major symptoms that causes people with PD to leave work.

Impact of maintaining work
"I am very tired at weekends, and feel unable to help look after my very boisterous 4 year old grandson. Also housework slides. I have someone who does my ironing for me." (S3)
"I feel a lot more tired when I get home from work in the evenings than I used to and this has reduced the things I do outside work." (S5)
"[maintaining work has a] Massive impact *[on other activities]. I just cant do what I used to I no longer have the physical energy to go to exercise classes after work or the Gym.*
I found that work took all my stamina with nothing left for the family. Therefore, I have increased my medication to give me a boost in the evening so my family don't just see the 'dregs'! We don't socialise much!" (S8)
"I am worn out by 9.30 at night and I do not go out very much at night. My husband has to do a lot more in the house than before." (S13)
"I don't get out as much as I did, all my energy goes into work." (S2)

To further explore the options available to people with PD, their experience of applying for new posts, part-time working and becoming self-employed were gathered.

Experience of options - new employment
"I've had that feedback from interviews. Even before I was diagnosed it was not what I said it was just that I didn't come over well. And should be more animated in your face as well."

(FG2R2)

"Fear! Most employers think that you will immediately start shaking and falling about. They often think that your mental capabilities are automatically affected. When I needed to change jobs (moved area) because I was not applying for management positions (I felt I wanted less pressure) and I explained why although given an interview, I sensed that I was not going to get the job." (S18)

"I saw a job that I thought sounded a good opportunity for a step up the career ladder. I was concerned that I would put myself under additional stress and that would worsen my symptoms, so after consideration, I did not apply. I would be obliged to tell any potential employer about my PD and I feel as if this would count against me in their selection process. As a result I feel as if I need to stay with my current employer." (S5)

"Since diagnosis I have wanted to apply but held back because I experience extreme nerves which I didn't previous to diagnosis. However I did apply and was treated very well. I gained the position and promotion." (S8)

"When I was diagnosed with Parkinson's it gave me a kick up the backside to get more money in an easier job. One of my colleagues showed me a job advert, and said you could do that and its even more money in [place] *we could afford a house to fit all the children so I applied for it, on the form I had to put down I had Parkinson's disease it wasn't a closed form it was available to the panel. Went for the interview had a very positive experience at the interview, didn't expect to get the job but was offered the job."* (FG1P2)

There were surprisingly few respondents who had experience of applying for new posts considering the number of people who were involved in the study. However those who did experienced both positive and negative reactions to their condition by potential employers.

Experience of options – becoming self-employed

"I should have done it earlier! I'm very happy that I retained control over events - and that I have more clients than ever." (S20)

"I'm contemplating returning to my own business of consulting which I had prior to diagnosis. I feel this will give me more control over the level of work I will undertake and remove the employer power - but not the power of clients. If this becomes an issue - I will try to adapt the services/business to suit if possible." (S4)

"I resigned from the partnership, believing that the situation would become increasingly unpleasant. I worked from home, took a number of clients with me and have made more money

> *in each of the last 4 years than in the 3 years of the partnership."* (S20)

Again, surprisingly few respondents tried to become self-employed, although the few who did described it as a successful strategy for managing their condition whilst being in employment.

Experience of options – going part-time
"I tried to reduce my hours, but could not earn enough or find a part time job suitable." (S18)   *"I'd been struggling with it for some time the getting up early the routine I couldn't manage 4 days a week and then knocked it down to 3…I had to push very hard for that."* (FG3R3)   *"If they had said to me would you like to come in later in the mornings or less hours then this would have been a great help."* (FG2R3)

A decrease in hours was also a solution for questionnaire respondents with 26.7% having tried a reduction in hours as a strategy for maintaining their employment. However, considering that fatigue was highlighted as a major issue surprisingly few people had requested or tried reduced hours. The reasons could be varied, not knowing how or what to request, a lack of knowledge regarding their rights or not knowing how this would affect their pension.

To assist with the decision making process for people with PD, the thoughts of respondents who had given up work were examined in order to offer a retrospective position. The data highlighted three themes arising from the consideration of thoughts about having left work, these were; regret, impact on self-esteem and lack of social contact.

Thoughts about having left work – regret and sadness
"Very, very sad." (S14)   *"Gutted"* (S17)   *"I worked such long hours as a HGV driver I didn't have a lot of spare time for fun now I've got loads of time but no money".* (S17)   *"Sorry because I had loved the job but glad because I was able to come to terms with the diagnosis of PD."* (S19)   *"I do miss it, it's nice to have individual pupils but its not the same."* (FG2R1)

Thoughts about having left work – impact on self-esteem
"Difficult to just be housewife again. Needed to boost my own moral, felt a little useless. Not needed, had to find identity again. I don't go out in the evening as much now, but that's my preference." (S6*)* *"Made me feel a lesser person, affecting my self esteem."* (S1) *"I'm coming to grips with this right now. I am having to redefine myself.".* (S12) *"I am still employable when certain things happened you're not totally unemployable… there's always something that you can do."* *(FG1R2)*

Thoughts about having left work - lack of social contact
"You suddenly don't see the people who you talk to all day long are no longer there." (FG2R2) *"I am aware I need to keep up out of work contacts or there will be a sense of loss if and when I do give up work."* (S2) *I've got one friend that comes down from* [place of work] *but she always seems busy I don't think she realises what it is like for me …she is still a part of it."* (FG2R2)

Questionnaire respondents also expressed regret about leaving work. Of the questionnaire respondents who left work due to PD 65% would like to have remained employed. Their reasons for wanting to remain in work were similar to those in the other two data collection methods, namely (in this order) self-esteem, financial, social contact, making a contribution to society and physical/mental stimulation.

6.5.3 *What does the literature say?*

The exploration of the data in this stage has highlighted several issues for consideration when deciding how, and indeed if, to maintain work. Fatigue has been identified as one of the major symptoms that cause people to give up work but then is also a factor affecting the work-life balance of those remaining in work. People have stated that they try and maintain work for reasons of finance, social engagement, self-esteem and stimulation. Respondents seem to regret giving up work and options that have been tried include going part time or becoming self employed.

The symptoms of PD that can affect work performance have been identified in Stage Two, however as fatigue has been raised as the major symptom which influences decision making when considering employment options it is worth revisiting current literature on the subject.

Fatigue has been acknowledged as a persistent problem for between 40-50% of people with PD (Friedman and Friedman 2001, Shulman et al 2002) and is frequently reported as one of its most disabling symptoms affecting not only physical activities but also cognition and emotion (Havlikova et al 2008b) and yet is often undiagnosed and untreated by neurologists (Shulman et al 2002). Although it can be experienced as a symptom in its own right, fatigue has often been associated with symptoms of depression, anxiety and apathy (Friedman and Friedman 2001, Havlikova et al 2008b, Hagell and Brundin 2009), indicating that often the people who experience fatigue are ill equipped to manage it due to the associated symptoms.

The fear of social withdrawal if relinquishing work or the subsequent regret of a decrease in work related social engagement once work has been relinquished was another key feature found in the data. It is now widely understood that often people with PD choose to withdraw from social contact due to a variety of reasons such as depression, apathy, impaired speech or embarrassment regarding their symptoms in general (Backer, 2006, Reese 1999, de Boer et al, 1999, Brod, Mendelson, & Roberts, 1998, Peto, Fitzpatrick & Jenkinson, 1997, Nijhof 1995). In most work environment social engagement cannot be avoided as individuals have to engage with colleagues, customers, patients or students and for the majority of people work represents their main social engagement opportunity. Therefore when work ceases and the person with PD does not replace this activity with other social activities due to their tendency for social withdrawal or their associated symptoms their opportunities for social engagement are considerably reduced, affecting not only themselves but their partner and family. This can have a negative affect on the symptoms of PD, a reduction in social activities has been found to be a risk for cognitive decline in older adults (Zunzunegui 2003) and may even prevent disability (Mendes de Leon, Glass and Berkman 2003).

The benefits of staying in work were highlighted in Stage Three as minimising the harmful physical, mental and social impact of having long-term absence from work due to sickness (Waddell and Burton 2006). A study of older adults (typically post retirement age) found that those who carried out voluntary work were less likely to become depressed (Musick and Wilson 2003). Work also promotes physical activity and

the relationship between physical activity and depression has been widely researched (Brosse et al 2002) and found to be an effective treatment for depressive symptoms, indeed, physical activity has a protective effect against depression for adults (Strawbridge et al 2002, van Gool et al 2007).

In Stage Three the legislation relating to the employment rights of people with disabilities was examined. Considering the legislation and initiatives available to help in the case of people with PD it would seem that retaining current employment and using the protection offered by the Disability Discrimination Act (1995) plus support from the Access to Work scheme would be the most beneficial course of action in this situation.

6.5.4 Stage Four Intervention

The patient will exit this stage with a decision they want to pursue, therefore the purpose of this stage of the intervention is to ensure that this decision is the best possible one for the individual, taking into account their lifestyle, their employment and their symptoms.

By this stage I already have a basic understanding from Stage One of what employment means to the individual (and more importantly what impact giving up that employment would mean) and, from Stage Two, how their symptoms affect their performance at work. Now there is an opportunity to reflect this understanding back to the individual and gather more detail, in addition to reinforcing, if appropriate, the need to stay in work to create a positive impact on symptoms. It is essential to have knowledge of PD symptoms and prognosis and the individual's circumstances to be able to extrapolate the relevant contributing factors to the decision making. The collected data highlighted a framework of questions that will enable me to guide the person with PD to consider the influencing factors in his/her decision.

Questions about Lifestyle

- What does work mean to the individual?

Does it represent his/her identity, is it an enjoyable activity or is it simply for financial reasons?

- Does the person need to stay in work for financial reasons?

Perhaps to support a lifestyle, a mortgage, children at university etc.

- When will this period of financial dependency end?

Perhaps when the children have finished University or when the person is able to claim their pension.

- Is work having a negative impact on other activities?

Is the level of fatigue experienced causing the individual to relinquish other activities in his/her life or causing difficulty to maintain other roles such as parenting?

- Does work represent the individual's main social outlet?

If he/she left work would the individual have any other social outlets, does he/she live alone, would he/she become socially isolated?

Questions about Employment

- What are the requirements of the job?

What are the demands both physically and mentally?

- What is the scope of the job?

What are the hours worked? Where is the job located?

- On what basis is the individual employed?

What type contract does he/her have? What are the terms and conditions of the employment?

- What is the employer's attitude?

Has the individual informed his/her employer? What was the employer's response? What has been the response of colleagues?

- What adjustments have already been made?

Have any adjustments been tried by the individual? How successful were they? Who initiated them?

- Does the individual get any support at work?

Are there any sources of help from line manager, human resources or union?

Symptoms

- What are the individual's major presenting symptoms?

What are the physical and cognitive symptoms experienced by the individual?

- How do these symptoms impact on his/her ability to do their job?

What is/are the specific impact of each symptom either individually or in combination on the tasks that the individual is required to perform?

- What symptomatic treatment is the individual receiving?

What medication is he/she on? When did the individual last receive a medication review?

- Does anything exacerbate the symptoms?

Does stress and/or anxiety have a negative effect on the symptoms? What causes stress or anxiety for the individual in the workplace?

The answers to this framework of questions, in addition to the information gathered from the preceding stages, provides a clear picture of why, and indeed if, the person with PD needs to retain work, the impact of maintaining work on their life and the effect of their symptoms on their ability to perform their job. In order to successfully reach a decision to pursue, I need to engage specific skills and techniques to enable the person with PD to talk about their aspirations as often they have been informed from several sources, including medical staff and their family that they should leave work. Utilising elements of a talking therapy, in particular Solution Focussed Brief Therapy (Miller et al, 1996) can help the person to visualise a goal regarding their employment and then formulate a decision.

Discussion of a realistic time frame is essential at this point. Are we looking at pursuing an option for six months or the next five years? Taking into account their symptoms, what is achievable? Often individuals state that they should leave work as they can't see how they can maintain their employment until their retirement age. However, as there is a strong evidence base to support the benefits of retaining employment for people with PD at this stage I will encourage them to think about a short term plan. Perhaps this might involve trying to maintain their employment for only the next six months or a year and that this short term plan will be beneficial to them.

If the person needs and/or wants to remain employed then it is clear from the literature regarding legislation and rights that it is in the individual's best interests to retain their current job (depending on contractual arrangements) rather than seeking new employment. However, from the data it emerged that some people have found becoming self-employed a successful way of managing their performance. Both of these options can be presented to the individual if appropriate, although for most people becoming self-employed is not feasible, so generally I have to consider how the individual is going to maintain their current post.

If the person does not want to maintain their employment, then, at this stage it will be a decision they have made having understood the options that are available to them so that they feel they have made a choice to leave, rather than feeling that they have no option but to leave. The intervention still continues however, to provide the individual with a successful exit strategy which will be further discussed in Stage Seven.

Summary of Stage Four Intervention

- Establish why the person with PD needs to work

- Identify job role requirements

- Establish a goal

- Identify a time frame

At the end of this stage narrative will have moved on from '*I have options…but what is the best one for me?*' to '*I have weighed up the options and have made a positive decision to stay in work.*'

6.6 **Intervention Stage Five**

Purpose of Intervention Stage Five - Support the decisions made.

6.6.1 Clinical Reflection

The need for this stage arose when I discovered that people with PD often displayed difficulty in taking forward their decision to retain their employment, or, to create and implement an action plan to maintain their employment. If the intervention ceased at Stage Four, although the individual would have received targeted information and support to make a decision in their best interests, they would struggle to implement the decision they had made. So in this stage of the intervention I assist the individual to create an action plan in order to implement their decision. This stage further supports their decision making process and validates the choices made.

Narrative at the start of Stage Five - *'I know what I want to do…now how do I take this forward?'*

6.6.2 Themes arising from the data

The collected data was examined for themes that were associated with implementing an action plan. The most pertinent issue seemed to be disclosing the diagnosis in order to implement a plan of retaining work, as it is important for the relevant people at the place of work to be aware of the diagnosis. Further analysis included why and when respondents decided to 'tell' and what their employer's reaction was to this news. In addition, the data revealed what has been helpful in terms of schemes that have been utilised, financial information required and changes to work that have been effective. When considering the factors affecting a decision to disclose the diagnosis, respondents highlighted the responsibility they felt about disclosing a diagnosis, particularly if it impacted on the legal requirements of their job such as using machinery or driving.

Factors affecting the decision to disclose the diagnosis – legal requirements

"Told my employer upon diagnosis after Union advice & because of insurance implications etc." (S2)

"Immediately after diagnosis. They requested a BUPA examination to consider my fitness to drive and to carry out my duties." (S14)

> *"On diagnosis, the occupational nurse nearly had a coronary until I got the letter from the DVLA saying I was fit to drive."* (S17)
>
> *"I had to tell them by law."* (S17)
>
> *"Fear of causing an accident at work. Can you imagine the consequences?"* (S14)

Some respondents identified the positive reasons to disclose a diagnosis. Respondents highlighted that it was less stressful to disclose than to continue to 'cover-up' the condition, or waiting to be 'discovered'. Other respondents suggested that disclosing gave them a sense of control and that it made a positive contribution to disability awareness.

Factors affecting the decision to disclose the diagnosis - positive reasons

> *"It's less stressful being honest and a determination to support the social model of disability."* (S2)
>
> *"I told them because I feel that if I was having a bad day then they wouldn't be critical."* (S3)
>
> *"If at all possible be honest with people about you PD issues. Having the disease is stressful enough without compounding things by keeping it secret and trying to move/act "normal." You have a new "normal" and that's okay! Plus you just never know who might have a great idea or contact for you."* (S12)
>
> *"I didn't want to hide from people. Also I am who I am!"* (S8)
>
> *"Basically honesty is the best policy. Respect for my colleagues and boss."* (S15)
>
> *"Just in case I needed some help. When you start taking different medications, they can sometimes have an adverse affect. I reacted very badly to an agonist and ended up collapsing at work."* (S18)
>
> *"They knew something was wrong -and I decided to exert control over events."* (S20)
>
> *"I wanted them to know exactly what was happening to me, I wasn't drunk or taking drugs but prescription drugs, I did it to educate people, not for sympathy. Because I was very rational about it, gave people sheets on it."* (FG3R5)
>
> *"I didn't have any reservations about disclosing my diagnosis. I always believed in letting people know for two reasons: first, you never know who has a family member with PD and can help you out with information and contacts, second, if you don't let people know, they jump to the strangest conclusions, like the people at the little league who thought I was becoming an alcoholic due to my bumbling, stumbling gait!"* (S12)

Having made the decision to disclose or not, some respondents disclosed immediately, some delayed for a varying period of time and others did not disclose at all. Some respondents felt unable to disclose their diagnosis or needed a little more time to disclose, they described their reasoning for this.

Disclosing the diagnosis - telling
"I was working for a company in [city] *and they sold out, another company bought it and I had the occasion to speak with my employer I told him immediately."* (FG1P4*)*) *"I told my employer by phone as soon as I got back from my Neurology appointment."* (S3) *"I told my colleagues and practice manager straight away as they knew I was going to see a neurologist and were quite concerned."* (S6) *"I told my 2 business partners the day after I was diagnosed."* (S20) *"I've been pretty open from the out-set."* (S8) *"I informed my employer and colleagues the day after my diagnosis."* (S19) *"I told them straight away."* (S13) *"I was upfront with my employers and colleagues as soon as I found out what I had*." (S12) *"I told my employer straight away to meet the obligations to them. Confidentially I told them but not my colleagues."* (FG3R1)

Some respondents felt able, or bound by duty to disclose their diagnosis however, others felt that they required some time to get used to the diagnosis first before sharing it with others.

Disclosing the diagnosis – delaying
"At first I didn't see that it had any relevance but later felt it was the right thing to do especially re driving a company car." (S10) *"It took about a month for the relief of knowing what was wrong and for the diagnosis to sink in after which time I felt it only right to inform my colleagues."* (S1) *"....although I know that there is protection under the Disability Discrimination Act, I was concerned that there were potential redundancies on the horizon and my disability may count against me. If an employer wanted to get rid of someone with a disability, they could give another reason."* (S5) *"I feared the worst that I may lose my job or status. I also thought... it's none of their business*

> *anyway!"* (S8)
>
> *"I was diagnosed early and didn't want to tell anyone at work immediately until I understood more about Parkinson's myself." (S5)*
>
> *"Not until about a year after."* (S18)
>
> *"I told my boss, immediate colleagues and the HR people eight months after diagnosis."* (S5)
>
> *"18 months after being diagnosed I told my employer."* (S10)

Some respondents felt unable to tell their employer at all for fear of repercussions, although they seemed unable to describe what they thought these repercussions might be.

> Factors affecting the disclosure – deciding not to disclose
>
> *"My employer and clients are not aware I have PD. I'm still in the closet."* (S4)
>
> *"I did not disclose my condition but kept it to very close family and friends."* (S15)
>
> *"Unless it is very apparent, then I would not tell them* [employers]. *Make sure you tell a close friend, just in case you have a problem. Never look for sympathy, always try and carry on as normal. It's not always easy, but people respect you for it."* (S18)
>
> *"Everything was alright really when I was first diagnosed I didn't tell anyone really, only my immediate family knew and the person I worked with that was it really."* (FG2R3)
>
> *"I hate telling people, I sometimes feel like a freak."* (S18)
>
> *"I was anxious about revealing my problems, at the time I was diagnosed no-one would have guessed as it was not obvious. I worried that I might be more closely scrutinised and even have my hours reduced or asked to leave. I loved my job and put a lot of time and effort into it."* (S15)
>
> *"She* [manager] *did say she wouldn't tell other members of staff, if I wanted anyone to know I should tell them. Well I am a fairly private person so a lot of people didn't find out for a number of years. I did however presume that the manager would inform the* [senior manager]. *For 6 years I continued to work there and none of the four* [senior managers] *ever mentioned it or asked how I was."* (S6)

Respondents revealed that when deciding to tell their employer the process was influenced by factors such as legal obligations (insurance, driving etc), a sense of responsibility to their employer and colleagues and taking control of the situation. Their

decision not to tell was influenced by a fear of losing their job, being 'watched' or being viewed differently. Responses varied greatly from telling employers immediately following diagnosis, to never having informed their employer of their diagnosis. Questionnaire respondents identified a wide time scale from receiving diagnosis to informing employer ranging from immediately to up to 4 years with the average being 3.6 years. This is an issue of concern as if a person with PD requires support and adjustments for their condition from their employer, then they need to disclose their condition. This lack of disclosure could prevent successful adjustments being made in the workplace to allow the person to remain in employment. To investigate if people with PD had reason to not disclose their diagnosis, the employer's responses of those who had disclosed were considered.

Employer's reactions - positive
"On the form I had to put down I had Parkinson's Disease it wasn't a closed form it was available to the panel. Went for the interview, had a very positive experience at the interview, again didn't expect to get the job but was offered the job." (FG1P2)
"They [employer] *have been brilliant and extremely supportive."* (S3) *"... initial reactions have been supportive."* (S5)
"As they had noticed something badly amiss, they [employer and colleagues] *were relieved when I gave them my diagnosis. I have received nothing but understanding and their unstinting support."* (S7)
"Disbelief from my colleagues. My [manager] *was sympathetic and didn't go into further detail about my job as I was still fully capable."* (S6)
"....they [employers] *were incredibly sympathetic and supportive."* (S10) *"They* [employers] *were shocked that someone so young could have PD. All levels of management were very supportive."* (S1)
"Company attitude exemplary - arranged new car and made it clear that I should keep them informed of any change in condition. Colleagues were generally sympathetic and helpful." (S10)
"All of my co-workers were supportive and stunned that I somehow had gotten this "old persons" disease." (S12)
"No- one has been anything less than sympathetic or tried to be helpful - unfortunately, even when I can cope with the task in hand there is always someone who thinks they can relieve me, mostly they mean well but sometimes it is so infuriating to have things taken away from you

because they deem I am not capable.” (S15)

I think response depends upon agenda. In general most colleagues are very supportive.” (S8)

The majority of respondents who described their employers and colleagues reaction to their diagnosis received a positive response but unfortunately some received a less supportive reaction.

Employer's reactions – negative

“…when I told them they didn't suggest any changes and sent me to see the doctor and he was more or less the same you can't work like that and that was it.” (FG2R3)

“Fear! Most employers think that you will immediately start shaking and falling about. They often think that your mental capabilities are automatically affected. When I needed to change jobs (moved area) because I was not applying for management positions (I felt I wanted less pressure) and I explained why, although given an interview, I sensed that I was not going to get the job.” (S18)

“My 2 business partners panicked. They assumed that I would quickly become a liability and that no clients would want to hire me.” (S20)

“They couldn't believe their luck when I told them, they said 'go home', they continued to pay me, and then I was made redundant in July with some others.” (FG1P3)

“…their reactions were varied. My employers did not have much information on PD and did not seem to want to know about it. My colleagues were more curious but did not go into it very extensively. (S13)

Generally, employers reacted positively to a diagnosis disclosure, the negative reactions were perhaps based on ignorance or economic motives. The results were then examined for sources of support that people with PD could use when trying to sustain their employment. The questionnaire responses highlighted that only 40% of respondents sought assistance and only 37% of respondents actually received assistance to remain in employment. They sought assistance from a variety of sources including; their work place (Human Resources, colleagues, managers 25%), Financial Consultants (17%), PDS 17%), Disability Employment Advisor at the Job Centre (12.5%), Union (8%), Doctor (8%) and occupational therapist (8%). Of those who actually received assistance to remain in employment, the assistance came from; their workplace (68%), PDS (9%), DEA (9%), Doctor (4.5%) and occupational therapist (4.5%). Of those who didn't

receive any assistance, 45% said that they would have liked to have been offered some help. The results were examined further for useful and less useful sources of support.

Sources of support - useful
"My immediate supervisor had a close friend who had Parkinson's so they were aware and knew about it. I did get some new equipment and that was from Employment Services. They got me a superduper chair it cost £400 they were very good. The physio, they paid for all that, somebody came into work for me. They were very good." (FG2R4)
"The offer of help is there if/when I need it, although there are no concrete arrangements in place yet. I have asked for a monitoring process to be set up so that I can have regular meetings with HR and tell them about how things are going, as well as having the opportunity to ask for specific help." (S5)
"Colleagues offered help with all kinds of tasks that I had to do. My bosses couldn't have been more helpful, allowing me to tone down my stress level by changing jobs 3 times in a 5 year period." (S12)
"They were very good at work, got me an occupational therapist, got me all sorts of special equipment." (FG2R4)
"My GP and PD specialist nurse have been brilliant as has the consultant and local occupational therapy lady." (S7)
"My PDNS, my GP and my occy health counsellor have supported me, listened to me, wiped my tears and generally "been there" when I needed them. Job Centre Plus are amazing. They are giving me funding for a support worker. The support worker will:- write my notes, drive in the PM." (S3)
"Got employment support from Access to Work." (S1)
"I spoke to a lady from the Scottish Resource Centre and she helped me." (S13)
"PDS Helpline were wonderful." (S14)

Some of the sources, that were found to be of use by some respondents, were found to be less useful by other respondents. The support received from healthcare professionals varied enormously.

Sources of support – less useful
"We went straight to the Welfare Officer at P.D Society we had had various conversations with him at open days and decided this was the time to talk to him and to be quite honest he wasn't

that much help." (FG1P2)

"I went to the P.D.S. to see if there was any way that I could get anything that would help me maintain the lifestyle and they sent me loads and loads of information and I got no further and ended up back at work it was all gobblygook." (FG1P4)

"[Employer] sent me to an occupational therapist who didn't know anything about Parkinson's at all. He asked if I wanted a lift in [place of work] and I said no thank you." (FG2R1)

"...the Doctor said you're not well enough to work or do the job so she wrote me a 3 months sick note and that was it." (FG2R2)

"I was advised by the consultant that I could improve the quality of my life by probably 5 years by giving up work, ...the idea of detaching myself from the work places wasn't very good." (FG3R9)

"....they sent for me at the Occupational Health and they said you can't work with what you've got and that was it." (FG2R3)

"The boss usually came to see me once a month but he never suggested going in later or anything like that." (FG2R3)

"I think if I look back my own personnel department could have been a bit more creative. They were very supportive for 12 months. Creativity could have been added."" (FG3R10)

"Employment departments are not always helpful, and try to offer menial jobs. Just because I wanted less hours, did not necessarily mean that I was not capable of doing my job properly." (S18)

The results were examined for the changes or adjustments to employment that the respondents felt enabled them to maintain their employment. Three key areas were discovered; working from home or flexible hours, changes to role or post and assistance to manage fatigue.

Useful adjustments - working from home and flexible hours

"Occupational Health have turned out to be very useful, directing my manager to be flexible in working time and in allowing me to work from home." (S8)

"Some of my work can be done from home anyway which is helpful. My hours are within my own control and (as a sort of outpost from Head Office). My new boss does not seem bothered as long as she can contact me and the work gets done." (S2)

"I now work from home on days I am not on the road this arrangement was to a large extent co-

> *incidental however I am able to take advantage of the flexibility especially first thing in the morning when I haven't got any flexibility!"* (S10)
>
> *"Starting in the morning was always the worst."* (FG2R1)
>
> *"Yeah, if they had said to me would you like to come in later in the mornings then this would have been a great help."* (FG2R3)
>
> *"I used to start at 6am and by the time I retired I was getting up at 4.30pm to get myself ready."* (FG3R10)
>
> *"I have flexible working arrangements regarding time and work venue. I get assistance if I'm going to travel long distances ie I take the train not driving. I receive time off to attend appointments; hospital, GP, physio."* (S8)
>
> *"During the last two years an in-house agreement with my manager allowed me to come and go as I as I deemed necessary. The last year I worked between 9am to 2pm."* (S1)
>
> *"A very flexible approach to the hours I worked, starting later and finishing earlier."* (S1)
>
> *"I had problems getting to work for the 8.30 start time."* (S8)

The main difficulty the respondents identified in relation to their working day was dealing with early mornings. Usually this was due to the timing of medication, respondents described having to wait for their medication to 'kick in' before they could start work, to cope with this some respondents had to wake up very early to give their medication time to be effective before starting work. The respondents did not highlight particular types of employment roles that were more difficult than others. Each role requires individual consideration of the components that cause difficulty.

Useful adjustments - changes to role or post

> *"I found that I was having a tough time working up to my own standards. I gradually worked at decreasing my stress and workload by shifting from one role to a less challenging one."* (S12)
>
> *"I still have a part time job, very unstressful."* (FG3R6)
>
> *"I changed to working on a lower grade."* (FG2R2)
>
> *"I was given a lighter job to do, and after a long struggle and a letter from my GP given a chair. I have also cut my hours to 20 a week."* (S13)
>
> *"I'm contemplating returning to my own business of consulting which I had prior to diagnosis. I*

> *feel this will give me more control over the level of work I will undertake."* (S4)
>
> *"...got to the stage where I couldn't handle anything and then I got to the stage where I couldn't stand up for very long without falling. So my job moved to a desk."* (FG2R6)
>
> *"I no longer had any contact with the members of the public."* (S1)

Useful adjustments – assistance to manage fatigue

> *"I was finding long journeys difficult and allowed journey time to nap in a service station."* (S10)
>
> *"....in a free period I have driven down the road in my car and had a snooze and felt fine.* (FG3R5)
>
> *"Just prioritised my day. Did more complicated things in the morning.*" (S3)
>
> *"I got a disabled car parking pass."* (S7)

The useful changes identified by respondents include; reducing hours, taking rest periods, flexible start/finish times, taking alternative/less stressful roles and working from home. The questionnaire results indicated that only 43% of respondents had adapted their working arrangements, and these adaptations were; decreasing hours (27%), changing role (20%), special equipment (17%), increased help from others (7%). Respondents who have requested changes have found that the adapted arrangements have been supported by colleagues and employers and have been successful. However, from the data it would seem that employers rarely suggest these changes.

The financial aspect of employment can, for some, be the most important factor in considering whether to remain in or leave work. It is explored in this stage of the intervention to highlight what respondents have found helpful regarding financial issues.

Financial issues – financial situation

> *"When I left work, I was dependent on my savings and my husband's income."* (S19)
>
> *"I became self-employed so I took a big tax hit in year 1 but apart from that I'm better off."* (S20)
>
> *"I dropped £600 per month on leaving."* (S1)
>
> *"I would be infinitely worse off if I left work. My pension is very small due to an unfavourable*

divorce settlement and not starting work till I was forty. I imagine this affects many women with disabilities." (S2)

"Believe it or not, since there are no longer so many deductions being taken out of my check, my net pay is the same!" (S12)

Many respondents were concerned about their financial future however only 9% of the questionnaire respondents had received financial advice.

Financial issues - pensions, insurance and settlements

"Research all aspects of employment rights. Check out your pension. Mine doubled if I had contributed for 5 years and left through ill-health!" (S6)

"One problem with doing shorter hours that I am a bit concerned about relates to the Permanent Health Insurance scheme that my employer provides. Basically, this is an insurance policy that pays you a percentage of your salary, up until age 60, if you are unable to work. I am not clear what effect going part time would have, since my salary would reduce and future PHI benefits may therefore be reduced. It may be better (at least financially) to keep working full time, but be prepared to give up all together a little sooner." (S5)

"I took a disability retirement. In addition, prior to my diagnosis I bought a salary protection policy from [provider] *which has provided 25% of my pre-retirement salary for two years tax free since my employer didn't contribute to the policy."* (S12)

"I was in a private health scheme which is normally still offered to you in retirement which is quite heavily subsidised I kept on with it, I got initial support with the Parkinson's diagnosis and initial treatment but then they said right that's it no more Parkinson's claims, they wouldn't cover me for it, put a clause on different to when we became members of that scheme they seemed to change the rules to suit themselves." (FG1P3)

"I have income insurance to 65 years. But I expect a fight with an insurance company as I expect them to look for every possible way to avoid payment or reduce the payment. This is speculation at present. It would amount to a substantial amount over 15 years." (S4)

"Prior to leaving I made extensive enquiries into what I would be entitled to. In practice though what I received and what I was told I would receive were different. My pension was added to my incapacity and taxed." (S1)

There appeared to be a dearth of reliable financial advice available, particularly when the person with PD is trying to investigate which would be the most financially rewarding method of withdrawing from employment. Surprisingly though, few people

actually sought advice. This is an important area of need for this group and is strongly advised by the respondents in this study.

6.6.3 *What does the literature say?*

In Stage Four the literature highlighting the tendency for people with PD to socially withdraw was identified (Backer, 2006, Reese 1999, de Boer et al, 1999, Brod, Mendelson, & Roberts, 1998, Peto, Fitzpatrick & Jenkinson, 1997, Nijhof 1995). If people with PD are struggling with being 'in the public eye' then this, combined with the non-motor symptom of apathy (as described in Stage Two) can make disclosing and explaining a diagnosis to an employer and colleagues very challenging and in some cases a withdrawal from employment preferable. In addition, it has been discovered that people with PD who have high apathy levels perform below the level of those with low apathy levels in measures of executive function (Pluck & Brown 2002). The constellation of sub-tasks that form executive functioning include initiation, problem solving, sustaining an activity to completion, abstract thinking and mental 'set shifting' (Cicerone et al 2000, The Society for Cognitive Rehabilitation 2004). People experiencing difficulty with this range of tasks would be ill equipped to independently create and then execute an action plan to maintain their employment. The tenacity required to cope with maintaining employment with a condition that is not only progressive but changes during the course of the day, simply does not exist.

In Stage Three the statutory support available for maintaining employment and the legislation surrounding employment rights was examined. The alternative work roles and options identified by respondents that were helpful could all be requested by a person with PD from an employer under the Disability Discrimination Act (1995). These requests would form 'reasonable adjustments' under this Act. The Access to Work scheme could provide practical and financial support for changes to working practice and to the working environment. However as identified in the data the person with PD is required to identify these adjustments themselves, they are rarely offered.

The available literature relating to finances, particularly benefits and pensions is varied, specific to the individual's circumstances and changes constantly. For example, at the time of writing the previously gathered literature relating to Incapacity Benefit is out of date, now replaced by the Employment and Support Allowance, introduced in October 2008. The interaction between state benefits, retirement benefits and private pensions is

an impossible one to generalise, the calculation and equations need to be made for a specific individual and is only accurate at that point in time. It is therefore unsurprising that the respondents found it difficult to source reliable information, but still is of vital importance.

6.6.4 Stage Five Intervention

In this stage of the intervention the individual will create his/her action plan and then requires support and guidance to initiate the implementation of that plan. The initial step in implementing any action plan is to disclose the diagnosis to an employer. Adaptations and changes to a job can only be made if the employer knows why they are needed. Although it would seem like an obvious first step, it was apparent from the data, and from my experience in practice that often there is a reluctance to disclose a diagnosis and a difficulty being open about having PD with employers and colleagues. However, it was also apparent in the data, that those who informed the work place immediately or soon after their diagnosis tended to get a sympathetic and positive response from employer and colleagues. Telling other people about their diagnosis of PD can throw up many challenges for the newly diagnosed, particularly if the person lacks information about the condition, or has cognitive or emotional issues. Some of the respondents spoke of having to 'get used' to the condition first, others described not knowing how to tell, or what to say to employers or colleagues, as they didn't yet understand the condition themselves.

In this stage I provide the person with PD with the evidence to support the need to tell (if they have not done so already). Respondents in the study spoke of stress when hiding the condition and relief when informing their employer. Stress can exacerbate some of the motor symptoms of PD (tremor) and the non-motor (anxiety). Not having to hide the condition means that the person with PD can request assistance when required. Respondents with positive attitudes disclose the diagnosis to employers and then use it as a way of 'networking', finding out more about the condition through contacts. I support disclosure by equipping the individual with information that I have written to give to their employer (appendix O) in addition to requesting other appropriate information from the PDS i.e. when preparing a teacher for disclosure we obtained leaflets and stickers for her young pupils from the PDS.

At this stage it is also useful to identify any other sources of support or allies. In some accounts I have heard, professionals and co-workers who should have been supportive have turned out to be anything but, however this is often based on ignorance. Individuals have reported being told by occupational health doctors and nurses that they should give up work, Human Resources have not offered practical support and even consultant neurologists have advised the person with PD to retire. This was reinforced by the data collected in this study. Sources of support were few and often offered little practical help. However allies in the workplace can be of vital support, they can be colleagues, line managers or Union representatives. Colleagues can provide day to day support and help to disseminate information to other colleagues. Line managers, particularly within larger organizations may have a more personal relationship with the individual and can offer alternative roles or adaptations to posts. Union representatives can be particularly useful to advocate for rights within the employing organization and to make a record of requested 'reasonable adjustments'.

The respondents described how vital it was to make small and manageable changes to their work role to enable them to maintain their employment. It was therefore surprising to find that only 43% of questionnaire respondents had requested such changes. This could be related to the difficulty experienced by some people with PD in disclosing the diagnosis, if a diagnosis is not disclosed then changes to work cannot be requested. However if the disclosure has occurred, then the next step is to consider appropriate changes to the work role.

In Stages One and Two, the person with PD has described what work means to them, and has identified the challenges of their job in relation to their current symptoms. In Stage Five I establish the requirements of the individual's employment role and enable him/her to create an action plan which may include some of the most useful options identified by the respondents in this study:

Options

- take an alternative role at work
- establish regular day-time hours
- change hours to avoid traffic and to fit in with timing of medication
- work from home
- reduce hours or days worked
– work flexi-time

Most of these relatively simple changes can easily fall within the 'reasonable adjustments' suggested by the Disability Discrimination Act (1995) and I would recommend considering the first three options as the initial approach to adapting work. I would encourage the individual to consider alternative roles that may be open to them within the employing organisation. The individual may be able to identify an alternative role that is easier to maintain, particularly if working in a large organisation, taking into account their symptoms e.g. changing to a post that involves less travel (fatigue when concentrating on driving or getting stressed in traffic) or moving from a 'front of house' role (increased anxiety when trying to control fluctuating symptoms in front of customers /students /clients) to a 'back room' job. Continuing with making allowances for symptom management, changing hours is also an extremely effective way of maintaining employment e.g. changing from a night shift crew to a day shift, or changing from shift work to fixed hours to enable a regular sleep pattern to be established. Some respondents had identified that altering their start and finish time to avoid rush hour traffic had made a huge improvement to their energy levels.

If it is thought that the fatigue experienced by the individual is so high that the above changes would not have a suitable impact then reducing hours worked may be successful. However this is not often a straightforward option when taking into account pension payments, or negotiating with an employer. However utilising the Access to Work scheme could be the answer as this scheme can facilitate the individual working reduced hours but, in some situations, still retaining their full pay. Depending on the needs of the role and the symptoms of the individual, the reduction in hours could be either by working shorter days, or fewer days in the week.

Many people with PD report that managing fluctuations is one of the most difficult factors of the condition. This can cause the individual anxiety when maintaining their work as they worry about how they may perform from day to day or hour to hour, and this anxiety can in turn exacerbate the symptoms. A solution can be to work flexi-time if the type of employment can accommodate this option. This gives the individual the opportunity to work when they are feeling fit enough, and, not have to take sick leave when they are not feeling that they can perform their role adequately. However, an additional benefit of this can be the reduction in anxiety. The individual will be relieved that if their symptoms are particularly restrictive that day they will not have to go to work, and can 'make the time up' another week. This reduction in anxiety may in itself influence the symptoms positively. I then discuss which of these options would be best

suited to the individual at this point in time and which might be considered in the future and it is important that these options are viewed positively rather than regarded as a sign of failure.

One of the major factors encouraging people to retain work is finances. It is difficult for me to advise people on their finances, however it is vitally important to guide individuals to seek independent and accurate information from the correct source. In my clinical experience I have found it difficult finding sources of accurate help for people who wish to get a prediction of their finances. Many people with PD have stated that they wished they had known more regarding their finances and in particular what terms they should have left on (voluntary redundancy, ill health retirement etc), and also to have known what benefits they would be entitled to if they left work under these terms.

This stage of the intervention challenges a range of my core OT skills including advocacy and education but in particular activity analysis and problem solving. The work role of the individual is analysed to discover what elements of the job the individual is having difficulty with due to their symptoms, this skill is essential when creating an action plan. In addition engaging the individual in a problem solving process can equip them with the skills to tackle future problems when they arise.

Summary of Stage Five Intervention

- Creation of an action plan

- Advise informing employer of diagnosis

- Identify sources of support

- Consider options for adapting job role

At the end of this stage the individual has moved on from *'I know what I want to do…now how do I take this forward?'* to *'I know what I need to do in order to stay in work'*

6.7 Intervention Stage Six

Purpose of Stage Six - Provide strategies to maintain the condition in the workplace

6.7.1 Clinical Reflection

I found in my clinical practice that often people required support around disclosing or not to their colleagues. This seems to be a particular issue for people with PD. I came across many people in the research who made the choice to leave work rather than tell their colleagues or employer about their PD. However, those who had maintained their employment successfully had been very clear with their disclosure in particular telling their colleagues how it would affect them and also what their colleagues could do to support them. When I talked to people who had left their employment often they stated a very limited range of seemingly inconsequential factors which contributed to their withdrawal. The incongruous factor in these events was that the person with PD had not asked their employer for help with these difficulties. Many of the people I spoke to expressed feelings of fear relating to confronting their difficulties at work with their employer. However, conversely, others talked of fear of being told that they could no longer complete their job role to an adequate level, and simply withdrew from employment before this happened.

Being able to make small and frequent changes to tasks in the work place can promote maintenance of employment. Often in the work place there is scope to swop duties with colleagues and that can make all the difference to a working day. A teaching assistant who had PD, who worked with children with special needs, was successfully managing a job she loved. She told me that she had been having difficulty helping the children to get dressed after PE due to reduced dexterity. So she swapped this task with another teaching assistant, and in return she put the equipment away after PE. She thought this was particularly amusing because she had swopped tasks with a strapping young male colleague who previously manhandled all the equipment which she now did. She said that the headmaster had some difficulty with this, watching her as an apparently physically disabled woman doing the more physically demanding job. But she explained that she had difficulties with her dexterity and not her gross motor skills. This was an excellent example of the importance of the individual having an understanding of how their condition affects them, and, being able to implement coping strategies.

Even though they can be very helpful in the workplace, I found surprising few people utilising environmental design or assistive equipment to help them to maintain their employment, or strategies such as fatigue management. This stage of the intervention is therefore required as I realised that people with PD need to implement strategies that will deal with the constantly changing symptoms that this progressive disease presents them with. A variety of strategies, techniques, equipment, environmental adaptations, support from colleagues and employers and changes to job role are required. People with PD require this stage of the intervention to enable them to implement flexible and effective changes which will support their employment in the future.

Narrative at the start of Stage Six – *"I can cope at the moment but how do I maintain this?"*

6.7.2 Themes arising from the data

The results were examined for assistance that the respondents found useful in maintaining their employment. The most useful forms of assistance fitted into the following categories;

- Making alterations to tasks in the workplace

- Using environmental design or assistive technology

- Managing fatigue and anxiety

- Dealing with employers

- Coping with a changing condition

All of these types of assistance are particularly relevant for people with PD to assist the long term maintenance of employment.

Altering tasks in the workplace
I tend to say very little at all [in meetings] *and if I do someone else tends to repeat what I say for me. Overall it's not been a negative experience, it's difficult to come to terms with it, because for me one of the main symptoms is my voice probably my own fault."* (FG1P2)   *"I had to give up working with acids and then work with dispatching much more physical actually but much less dangerous… less accuracy was needed… got to the stage where I couldn't handle anything and then I got to the stage where I couldn't stand up for very long without falling. So my job moved to a desk."* (FG2R6)

> *"I have meetings that I have to be at, I try to avoid making them before 9.30am I have to go to [locations 40+ miles away] I have to drive there which is a trial, I take the medication first thing in the morning so I can drive all the way there and be able to talk to people."* (FG1P2)
>
> *"Handwriting was an issue to me and we discussed strategies to avoid having to write.*" (FG3R5)
>
> *"I do tasks at a time appropriate to how I am. i.e. It's not ideal to take the coffee out to a teacher on playground duty when I know I am having a bad patch, or trying to put tights/socks on a child after PE."* (S15)

Less than half of the questionnaire respondents managed to adapt their working arrangements. This adaptation consisted of decreased hours (26.7%), special equipment (16.7%), increased help from others (6.7%) and changed role (20%). The successful changes to working arrangements that the respondents have made have been relatively simple and specific to problematic symptoms.

> Environmental design and equipment – successful
>
> *"All telephone calls I record and transfer to computer."* (FG1P4)
>
> *"They were very good at work got me an occupational therapist got me all sorts of special equipment."* (FG2R4)
>
> *"I did get some new equipment and that was from, work organised it. It was from Employment Services they got me a superduper chair it cost £400 they were very good."* (FG2R4)
>
> *"This year in our new high tech classroom I've been using the PowerPoint displays and projector in the ceiling you know and the facilities which have allowed me to stay in control. I think that there are strategies that will allow me to last longer."* (FG3R5)
>
> *"An automatic car also fitted with a modification to allow use of indicator from both sides. I could have had further modifications but do not require them."* (S10)
>
> *"I have been supplied with and trained to use Dragon Naturally Speaking ."* (S16)
>
> *"Yes through the job centre scheme (forgot the name!) I received a voice amplifier system to enable me to be heard in large groups. My job involves some public speaking."* (S8)
>
> *"....given a chair instead of having to stand for 5 hours."* (S13)
>
> *"I drive an automatic car - for how long this will last, I don't know but it keeps me very mobile and lets me carry lots of gear around. I've tried voice recognition software but I have not been impressed."* (S20)

Again, echoing results highlighted in previous stages of the intervention, surprising few respondents had investigated the use of assistive equipment to help them carry out their job. In the questionnaire responses only 16% had utilised special equipment in their work. The successful equipment had generally been given by the Access to Work Scheme.

Environmental design and equipment – less successful
"Have tried to master voice typing software. This has not proven all that successful because it requires so much time to train the software. It's not quite up to the technical and scientific language required. I'm sure it will soon. The software capability is doubling every 18 months-so I'm told." (S4)
"There is access to work, I've got a voice activated computer the county council paid for most of it....some of the shorter words can get misinterpreted it's very humorous actually as it invents very different sentences. It can be something about a very different subject. Am not sure whether I get tired or the computer does. It's a bit tragic then when you have to admit to people that 'my computer doesn't understand me'." (FG3R4)
"I use software but my voice varies so much throughout the day due to the medication or whether I'm tired so I can sit at the computer with headphones on trying to get it to register my tone of voice when really I could have used that time to hit the keys one at a time to do what I wanted it to do." (FG1P2)
"I don't write at all, I have voice recognition on my computer which 90% of the time doesn't recognise what I am saying, I type alternatively very slowly or very quickly depending on the time of day." (FG1P2)
"They made some effort to accommodate, voice equipment and stuff like that but I had to wait a year and have a review and all sorts of things it was only a £50 piece of software. They bought all sorts, but when I got it didn't work properly it took no account of deadlines things like that." (FG2R2)
"He [employer] *sent me to an Occupational Therapist who didn't know anything about Parkinson's at all. He asked if I wanted a lift in the school and I said 'no thank you'."* (FG2R1)

Voice recognition software has been of mixed success. It has obviously been suggested to the person with PD to assist with dexterity problems affecting writing however, this 'assistance' has brought its own problems. This is probably due to the lack of specialist knowledge that the Access to Work personnel have regarding PD which causes them to identify a specific impairment in isolation to the rest of the condition i.e. considering

dexterity impairments but not the voice impairment or vocal fluctuations associated with PD.

Many respondents have and are experiencing fatigue and stress/anxiety, 28.3% of questionnaire respondents reported that they had left work due to fatigue or anxiety/stress.

Fatigue and anxiety management
"I no longer have any contact with the members of the public." (S1)   *"Yes, in a free period I have driven down the road in my car and had a snooze and felt fine."* (FG3R5)   *"Just prioritised my day. Things I needed to do I do in the morning."* (S3)   *"Try to relax. Anxiety can be a real problem and should be avoided if at all possible."* (S11)   *"If at all possible be honest with people about you PD issues. Having the disease is stressful enough without compounding things by keeping it secret and trying to move/act 'normal'."* (S12)   *"I saw a job that I thought sounded a good opportunity for a step up the career ladder. I was concerned that I would put myself under additional stress and that would worsen my symptoms, so after consideration, I did not apply."* (S5)

Concern over increased stress and performance at interviews has held respondents back from applying for posts. However few are implementing fatigue or anxiety management strategies.

Dealing with employers - negative
"...it's the voice because you sound sort of bored less enthusiastic. The interviewee should have more training. It's like stress can set your tremor off which it would normally do, if they knew about that then they could disregard it as 9 times out of 10 it wouldn't be happening." (FG2R2)   *"I would like to go back* [to work] *but I think it would be part-time I have, like I said, been shortlisted for every single one but didn't get them. As I say they were on a lower grade because I was on quite a high grade previously."* (FG2R2)   *"I've had that feedback from interviews. Even before I was diagnosed, it was not what I said it was just that I didn't come over well. And should be more animated in your face as well."* (FG2R2)   *"Perhaps a leaflet about the early stages of Parkinson's would be helpful to tell employers 'I*

have this but it won't make a lot of difference this year, but it may next', obviously just to make them aware that I have a disease." (FG3R4)

"They [employers] *are frightened."* (FG3R10W)

"Certainly the invisibility of the disease initially. A lot of people/friends say they wouldn't notice there was anything wrong with me as long as I stay sitting down. I'm fine with that. The embarrassment is I just stagger around a lot. But telling people about the condition… to this day I don't have a neat 2 line as to what Parkinson's means…to explain that to an employer, I don't think they understand to a degree I don't think they know anything." (FG3R7)

"Employment departments are not always helpful, and try to offer menial jobs. Just because I wanted less hours, did not necessarily mean that I was not capable of doing my job properly." (S18)

Some respondents found their employers to be supportive of their condition.

Dealing with employers - positive

"[My employers were] excellent. They spoke to me prior to the interview to asses my requirements. Candidates were to be given a presentation on the day to deliver. following discussion about slowness and size of handwriting this was changed. All candidates were given the topic in advance." (S8)

"[my employers are] Excellent as long as I keep them aware of any changes." (S10)

"One of my managers saw me as a competitor to his role. His reaction was to 'encourage' me to work from home permanently. This was a little premature and a little too forceful. Subsequently, I have applied for and gained a new post …a higher grade too! My employers were very helpful in the interview process. They were great and I have gained a massive amount of confidence through this." (S8)

"…on the form I had to put down I had Parkinson's disease it wasn't a closed form it was available to the panel went for the interview had a very positive experience at the interview, again didn't expect to get the job but was offered the job." (FG1P2)

"I was working for a company in Leeds and they sold out, another company bought it and I had the occasion to speak with my employer I told him immediately and they have been very supportive, bought me recording machines at work. My writing is appalling, to the point where I can sign my name and that it, the rest of it is not too bad, whenever I get any problems at work they give 100%, at least that's what they appear to do anyway, they haven't showed me the door yet." (FG1P4)

From the data, employers need reminding that this is a changing condition and simply making one alteration isn't enough. It would seem that those respondents who have discussed their condition with their employer/potential employer and continue to do so have been successful in making suitable and appropriate adjustments. The respondents have identified that employers/potential employers require information about the condition which would also be useful in an interview situation.

Suggestions regarding dealing with employers
"When you first tell your employer about your PD, tell them what PD is and explain that its progress is different for each person. That will mean that no-one can say how much effect there will be in the future on your ability to do your job and what the time scales will be. I suggested an arrangement for periodic reviews - say every 3 or 6 months - to have a meeting to give you a chance to tell them how you are being affected and to ask for specific support with aspects of your job. It will also give the employer chance to tell you how they feel your job is being affected, so that you can work together to find the best courses of action going forward. Most of all, keep a positive attitude." (S5)
"…really I needed someone to sit down and look at what transferable skills I have and how they could be transferred, I've gone down so many avenues its bizarre. There wasn't one central person…no contact point at all." (FG3R1)
"…also maybe a campaign to tell employers through manufacturing, engineering a little flyer is this happening in your workplace?" (FG3R9)

One of the main issues identified the respondents was the difficulty they had in maintaining their employment with a condition that is not only progressive but which can change several times over the course of a day.

Coping with a changing condition
"The other thing as well is when you have Parkinson's you yourself don't know when you're going to be off. It is different so… you can't predict…. You just can't do it." (FG3R8)
"They [employers and colleagues] *don't know what's the matter with you, one minute your fine the next you're not."* (FG3R2)
"I'm better on a morning, by the afternoon I've switched off." (FG2R5)
"I type alternatively very slowly or very quickly depending on the time of day. I can't go to meetings that are the wrong time of day for me, some people understand, others don't." (FG1P2)

> *"I loved the job and could have done it at home. When you having a good patch do it then, an hour or so and then start again if you work from home just pace yourself."* (FG2R2)

The respondents identified a range of issues that require deliberation and action when a person is trying to maintain employment with a complex progressive condition. These issues and the actions suggested by the respondents will be incorporated into this stage of the intervention, and considered in the literature.

6.7.3 What does the literature say?

The collected data highlighted the need for people with PD to discuss their condition with their employer in order to implement successful strategies for the maintenance of employment. In a survey by the PDS of the 23.4% of people under 65 who were still in employment, only just over half had discussed their diagnosis with their employer. Over half of the respondents told their employer when they were diagnosed and unfortunately 10% of respondents said they had experienced discrimination from management at work since they became aware of their condition. However 61% said their employer had provided them with help or adjustments to help them stay employed but surprisingly 33% felt it had not been necessary. Adjustments that employers had made included a change in hours, change in job/duties, working from home offered, improved seating and equipment (PDS 1998). When asked about the attitudes of colleagues towards them when they know that they have PD, 40% experienced understanding and helpfulness and 18% had experienced negative attitudes such as intolerance, apathy, ignorance and hostility of colleagues. Comments by respondents included that there are 'varying attitudes depending on their knowledge of the condition', 'people are afraid to offer help in case they offend you, and 'people do not understand the on/off periods' (PDS 2002).

The non-motor symptoms identified by the respondents such as anxiety and fatigue have been estimated to occur in between one third and half of all patients with PD (Shulman et al 2002, Jones et al 1999 in Percival and Hobson 1999, Kostic et al 1994). People report that their sleep pattern has been reversed i.e. sleeping during the day and awake at night. Many report falling asleep in the early evening and waking in the early hours of the morning. Fatigue, in some cases, is of course linked to insomnia but in others it would appear to be unrelated to a lack of sleep and linked to the increased cognitive and

physical effort involved in performing everyday activities, or associated with the 'off' state (Witjas 2002).

Anxiety in people with PD has been linked to fears about managing the condition in addition to fears about physical deterioration in the future. (Lloyd 1999 in Percival and Hobson 1999). As anxiety is often experienced during the early stages of the condition by people of working age they could contribute to both the ability to engage in employment and the ability to develop coping strategies to manage the physical and social symptoms impacting on employment. Often exacerbating feelings of anxiety is the feeling of embarrassment that many people with PD describe. A British survey found that 42% of sufferers felt embarrassment due to their PD (Peto, Fitzpatrick & Jenkinson, 1997) with 48% reporting a need to avoid public situations, whilst in a Dutch one in four sufferers reported feeling embarrassed by their illness (de Boer et al, 1996).

Interventions aimed at dealing with psychological symptoms such as stress, by promoting active coping methods, cognitive restructuring and relaxation can be effective and can be integrated with medical treatment (Ehman et al 1990, Ellgring et al 1993). These techniques could be incorporated into the work place. Superior emotional well-being in PD has been found to be positively associated with perceived control over symptoms (but not over disease progression) (Wallhagen & Brod, 1997) and with active (cognitive and behavioural) coping strategies. So incorporating effective coping strategies to maintain employment may positively influence the perceived control over symptoms. Active coping has been found to predict function in PD after one year (Schreurs, De Ridder & Bensing, 2000).

The legislation supporting requests for changes to work roles and the schemes available to assist the funding of alterations to the workplace or adaptive equipment has been identified in Stage Three of the intervention.

6.7.4 Stage Six Intervention

The purpose of this stage of the intervention is to encourage the individual to develop a sustainable approach to remaining in employment. In the previous stage, the individual was prompted to disclose their diagnosis to their employer, and, to make small and manageable changes to their work role which may serve as a 'quick fix'. However, in Stage Six, the person with PD will devise a planned, long-term strategy and consider how to implement it in the workplace.

This stage of the intervention involves a very complex coordination role, and, requires knowledge of systems and a great deal of tenacity. Advocacy is required from the occupational therapist to promote the requirements of the employee, and, it is often necessary to attend employer/employee meetings. Frequently employers are sympathetic and want to at least be seen to be supportive, but simply don't know what their employee requires or where to source help.

The first part of this stage of the intervention is to ensure that the employer and colleagues have been informed of the diagnosis, disclosure of which was encouraged in Stage Five. To support this disclosure, employers should be given relevant information which will help them understand the needs of the person with PD. This is where a specialist occupational therapist can use his/her knowledge of PD, relevant legislation and activity analysis, to advise the employer of the most appropriate ways of supporting their employee. Having knowledge of the person with PD's job requirements and their current difficulties from the previous stages of the intervention, will enable the occupational therapist to give specific guidance to the employer. This guidance will include education so the employer will understand the impact of the symptoms experienced by their employee, and, the variability of the condition. Suggestions will be made regarding alterations to the job role or tasks that perhaps the person with PD has identified themselves. The data collected in this study suggests that if the employer has a flexible approach towards supporting their employee with PD, this can promote the maintenance of work. If necessary, reminding the employer of the requirements of the Disability Discrimination Act can prompt the employer to adopt a positive attitude.

The instigation of regular reviews should then be initiated. These should be between the person with PD, their employer and other individuals that the person with PD has identified as a source of support (see Stage Five) such as a colleague, union representative or someone from Human Resources/Personnel. The reviews can take

place as frequently as required, which may be every four months, six months or yearly. These reviews are essential in promoting a sense of control in the person with PD and the purpose of the review is to pre-empt difficulties that they may be encountering so that they can request adjustments, or changes, from their employer at regular points, rather than wait for their employer to approach them when they are having difficulties at work. In this way the person with PD can alert their employer to changes in their condition, alleviating the anxiety of waiting for someone to notice that they are struggling or failing. These reviews can highlight the need to utilise schemes such as Access to Work, or private/insurance funded services, which may be useful at various stages of the disease progression.

In addition to liaising with the employer to facilitate maintenance of work, specific symptom management strategies should be adopted by the person with PD. Effective strategies highlighted by the data, literature and clinical experience include fatigue management, anxiety management, environmental design, assistive equipment and pharmacological management. All of these strategies can be introduced by the specialist occupational therapist.

Fatigue management should be a pro-active strategy that is implemented early in the course of the condition. Elimination of unnecessary tasks that fatigue, timing of tasks and rest periods are essential elements of this strategy and a flexible approach should ensure that it is effective throughout the course of the condition, and beyond employment.

The earlier stages of this intervention should highlight anxiety triggers for the individual which can be dealt with by altering roles. Triggers that cannot be ameliorated by this method may require tackling by utilising traditional anxiety management techniques.

The occupational therapist can assess the person with PD work environment and prescribe alterations. These alterations may be simple and cost free e.g. repositioning work stations or other furniture, or may have a cost attached if specialist equipment is required. The Access to Work scheme can provide support with funding for necessary alterations. As discovered from the data, adaptive equipment has been found to be of mixed success, particularly voice activated computer software, however technology is developing constantly and other human/computer interface systems may emerge. Ergonomic workstations and chairs have been found to be useful and are easily sourced and supplied. The occupational therapist can prescribe these or the specialist staff

employed by the Access to Work scheme can assess for this equipment and provide support with the cost.

Encouraging and supporting the person with PD to take an active role in the pharmacological management of their condition is an essential coping strategy. The approach to medication for PD is, usually, a cautious use of L-dopa due to the side effects experienced with protracted use. However, in partnership with their PDNS or consultant, the individual should consider the options available, and, may prefer initiating L-dopa earlier in the course of the condition in order to maintain employment. A referral to the PDNS or consultant will be required for this discussion, and this is often the first time the person with PD realises that they can, and need, to be involved in their own symptom management.

At the end of this stage of the intervention the person with PD will have established a sustainable strategy for maintaining their employment for as long as possible or desired. However, PD is a progressive condition and at some point a withdrawal from the workplace may be necessary.

Summary of Stage Six Intervention

- Provide advocacy

- Support disclosure

- Implement strategies to maintain the condition in the workplace

> At the end of Stage Six the narrative will have moved from: *"I'm staying in work, but how do I maintain this?"* to *"I have strategies that will enable me to remain in work and respond to changes in my condition now and in the future."*

6.8   Intervention Stage Seven

Purpose of Stage Seven - facilitate a positive withdrawal from the workplace

6.8.1   Clinical Reflection

This stage of the intervention was created to assist the person with PD to leave work at the right time for them and for that to be a positive decision. I realised this stage was required when I repeatedly heard people expressing regret about leaving employment. Often people reflected on this more than a year after the event, at a time when the immediate stress around leaving work had diminished and when they felt as if they were managing their condition better. People with PD have commented that they "had to" leave employment and that they could think of no other options. The intervention described in Stages One to Six will enable people with PD to maintain their employment for as long as they wish to, or is practicable to. However, the intervention would not be complete without consideration of the exit from work, and, post employment occupation. As an occupational therapist I value the use of activity in people's lives as a way of maintaining health, and also as an indication of health. I realised that when people with PD left work they did not replace the work with other activities that may be beneficial to their condition. People with PD who were not in employment carried out activities that were inactive and solitary, that in turn were prompting social withdrawal and decreased mobility, which are issues typically associated with PD. Therefore this stage of the intervention is required to achieve a successful exit strategy and, subsequent adoption of activities that will provide a beneficial effect to the symptoms of PD.

Narrative at the beginning of Stage Seven – *"I am leaving work, what next?"*

6.8.2   Themes arising from the data

The data was examined to discover the impact that PD has on an individual's leisure or social activities and also what further impact the maintenance of employment has on these activities. Finally an investigation of the types of activities adopted or relinquished once the individual has left work was undertaken.

The effects of PD on leisure activities
"I move slightly slower otherwise I have maintained previous hobbies although choreographer for music society is a bit tricky!" (S10)
"Just cut down on my spontaneous events as I now need a little more pre-planning." (S11)
"I had to give up badminton, I use to go swimming but I've had to give that up because I find getting dried, and changed, in a communal changing area little bit embarrassing being slower, and plus the fact I can't co-ordinate." (FG1P2)
"I was really sort of nervous about going to these groups [creative writing] *because you have to read out what you have written. If I feel nervous, I feel really self conscious because I really don't like reading out anyway. But it wasn't too bad."* (FG2R2)

The questionnaire respondents identified the overall effect that PD had on their leisure activities, 8% stated no effect or positive effect, 43% stated a gradual curtailment had occurred and 37% responded that they had ceased all or most activities. The reasons questionnaire respondents gave for giving up activities were, physical reasons such as fatigue, stamina or tremor 81.7%, psychological reasons such as embarrassment, lack of motivation or confidence 33.3%, other reasons such as transport, time or financial 13.3%.

The effects of maintaining work on social/leisure activities
"My wife feels a bit fed up that I go off to have a sleep, she's wonderful but I'm a bit of a drag going to sleep" (FG3R8)
"I am tired when I get home on an evening. We are wanting to play badminton again…
I still want to try it, I've given up the ghost on the squash." (FG1P4)
"I go swimming once or twice a week, Tuesday evenings after work as I find that I become progressively tired during the week and by Friday I'm wasted. It depends what we've been doing in the evenings."   (FG1P2)
"I don't have many leisure activities if I have time I usually get home [from work] *and play on my computer, bit sad really."* (FG1P2)
"I am worn out by 9.30 at night and I do not go out very much at night." (S13)
"I feel a lot more tired when I get home from work in the evenings than I used to and this has reduced the things I do outside work." (S5)
"Massive impact. I just can't do what I used to, I no longer have the physical energy to go to

> *exercise classes after work or the Gym. I found that work took all my stamina with nothing left for the family. Therefore, I have increased my medication to give me a boost in the evening so my family don't just see the 'dregs'!"* (S8)

Even if the individual is able to cope with the impact of the symptoms on their work, the problem of fatigue is then 'shifted' or displaced to other parts of their lives and the impact of maintaining employment is the loss of social or leisure activities. In the questionnaires, respondents (both employed and unemployed) identified the types of leisure activities that were given up following the diagnosis of PD. They were; sport (68.3%), social activities (26.7%), DIY/home/garden (10%), creative activities (10%) and travelling (8.3%). There was a considerable change in the type of activities that people with PD engaged in as their condition progressed. There was a significant difference between certain categories of leisure activities pre and post a diagnosis of PD. Respondents reported an increase in sedentary hobbies, a decrease in social activities and a decrease in sport.

Activities adopted following withdrawal from work
"I was now at home 24 hours a day and once the medication settled down I was desperate to keep my brain active. I joined the University of the Third Age where I taught Beginners German, learnt Italian, joined a Quiz Group; Geology Class; Gilbert & Sullivan group. I also joined the Committee and was Publicity Officer, Membership Secretary and Newsletter Editor." (S19)
"I try to exercise daily, either at a health club or in the neighbourhood. I read and go to the library. I take care of the house and the grocery shopping. I garden. I make movies for nonprofits. I golf once in a while (badly.) I love to travel and really want to start doing that again. I watch my kids play sports." (S12)
"It's only been 2 months so am just getting use to it. I do some gardening for elderly neighbours; have been assisting the PD branch secretary on various endeavours and am archiving my photographic collection. And the new football season has started with matches to attend." (S11)
"Not on the scrapheap yet but I have taken on unpaid jobs in society which is the grey matter still ticking over and just getting involved in things where I can. I have become more computor adept." (FG1P1)
"I slipped nicely into the role of a church warden, day to day administration of our local church, still a variety of management skills required. The handwriting skills has disappeared

and at the same time my artistic skills really developed and I started running an art class which is satisfying." (FG1P1)

"I would like to think voluntary work but I think that would affect my benefits if you do voluntary work. Might think might not get your benefits, I find that really restricting." (FG2R4)

The questionnaire respondents who were not in employment, filled their time after leaving work with a range of activities which reflected those described in the above text box. These included voluntary activities (32.4%), homemaking (32.4%) sedentary hobbies (24.3%), social activities (18.9%) sport (13.5%), further education 5 (13.5.3%), travel 4 (10.8%) and being a carer (8.1%). It is interesting to note however that the number of hours spent on leisure activities prior to (17.5) and post (17.1) PD remains the same. Even though the respondents are losing employment it does not appear that they are spending longer on their leisure or social activities.

Most respondents felt that there were benefits in maintaining leisure activities (87%). They identified these benefits as being physical fitness (55%), mental stimulation (41.7%), social contact (28.3%), improved self-esteem /confidence /well-being/self-worth (26.7%). Respondents reported positive benefits in having leisure activities, however the number of hours spent carrying out leisure activities did not increase when the person with PD had left work.

6.8.3 What does the literature say?

Warr and Jackson (1987) identify three different adaptations to job loss, these being; constructive adaptation, resigned adaptation and despair.

Constructive adaptation is the most beneficial adaptation to a withdrawal from the workplace. The individual takes positive steps to ensure they remain occupied in social, leisure or voluntary activities. Resigned adaptation is where the individual feels a loss of autonomy and a sense of incompetence but without depression. The third adaptation, Despair, is where the individual's mood and aspiration are at depressed levels. Obviously constructive adaptation is the aim of this stage of the intervention and individuals will receive support to maintain activities and direction to engage in new, appropriate and beneficial activities.

Some people with PD will withdraw socially (Nijhof 1995) and in one study, social phobia was diagnosed in 50% of participants with PD (McNamara et al 2006). In addition, when considering the importance of social activities to people with PD, it has been found that they were less likely to rate social contacts and leisure activities as 'extremely important life goals' than age-matched controls (McNamara et al 2006).

The majority of literature regarding disability and leisure is focussed on sport for disabled people. Leisure is often identified as exercise in medical and social literature and many of the respondents in this study reported a reduction in their sporting, or exercise related activities. Low levels of participation in exercise have been reported in other studies by people with neurological conditions (Kosma et al 2004, Rimmer et al 2005). The health concerns related to a sedentary lifestyle of the general population also apply to people who have PD (Elsworth et al 2009) with the added implication of social withdrawal if people are not participating in activities outside the home. It has been found that exercise can improve performance in activities of daily living (Crizzle 2006), so overall maintenance of exercise related activity, particularly if a sociable exercise activity will be beneficial to people with PD.

The reasons given for the low level of exercise tend to be referred to as 'barriers', and again echo the findings of this study. Barriers to participation in exercise have been identified as embarrassment (Elsworth et al 2009) and inertia (Lees et al 2005) which could be interpreted as apathy in PD. Some studies identify access to the buildings in which these activities are carried out as being a barrier (Rimmer et al 2005), however that was not reported as a barrier in this study by participants, so this stage of the intervention must consider the intrinsic barriers to leisure activities identified in the literature and by participants in the study.

6.8.4 Stage Seven Intervention

When considering the literature, and the results of the study, the indication is that this stage of the intervention is essential. When people with PD leave employment the beneficial impact (as identified in Stage Two of the intervention) of this activity is lost. The literature highlights that social withdrawal and decreased participation in exercise-related activities is a strong possibility for this group, and I have found that is certainly the case in my clinical experience. When adapting to the loss of employment, I have found that the 'despair' identified by Warr and Jackson (1987) tends to be typical in

people with PD. They are then unable to fill the void left with leisure or social activities, and become increasingly isolated, low in mood and with deteriorating physical function. The purpose of this stage of the intervention therefore is to facilitate 'constructive adaptation' (Warr and Jackson 1987) to their withdrawal from employment.

A plan of withdrawal from work is required, and, although this is the final stage of the intervention, consideration of the withdrawal needs to occur throughout all the stages of the intervention. From the data, it would appear that managing work roles is leaving people with little energy to maintain their leisure and social activities, therefore the impact of this should be considered and highlighted to the individual. In Stage One, the person with PD begins to explain what their employment means to them, and it is important to maintain that awareness when planning an exit strategy and beyond. If a person conceptualises themselves purely through their work, then, when they leave, the loss of role can be hard to cope with.

An identity and a range of activities outside of work should run parallel to work, so that when work is relinquished the individual has an identity and a range of activities to engage in to replace work. These activities may include alternative, part-time jobs, voluntary work, or education, in conjunction with existing social and leisure pursuits that can be developed whilst the person is still in employment. However, this plan must take into account the fatigue levels of the individual. The coping strategies that are developed during Stages One to Six of this intervention can equally be applied to leisure activities. If the person with PD has used techniques and strategies to manage their work effectively then these can be transferred to other activities in their life.

This final stage of the intervention facilitates a positive withdrawal from the workplace, with the individual feeling in control, and making an informed choice, accompanied by an action plan to replace employment with other activities.

Summary of Stage Seven Intervention

- Facilitate constructive adaptation to the withdrawal from work

- Create a plan of withdrawal

- Develop beneficial activities to replace employment

- Transfer coping strategies

By the end of Stage Seven the narrative will have moved from *"I am leaving work, what next?"* to *"I am making an informed choice to leave work and have a range of beneficial leisure activities to engage in."*

6.9   Conclusion to Chapter Five

The collected data has indicated the need for the development of an intervention to promote, and support, the maintenance of work by younger people with PD. This chapter has modelled such an intervention. The intervention moves the narrative of the person with PD who is considering giving up work from

"I can't do my job and I have to leave."

to

"I have strategies that will enable me to remain in work and respond to changes in my condition now and in the future."

or, if the person is leaving work, to

"I am making an informed choice to leave work and have a range of beneficial leisure activities to engage in."

This change of narrative is facilitated by providing staged and targeted intervention. These intervention stages have been created through examination of the data collected regarding the employment experience of younger people with PD. Each stage of the intervention is summarised in table 3, alongside the change in narrative, and the specific data and literature which has informed that stage.

The results of this study have demonstrated a consensus around the most difficult symptoms to cope with in employment. Fatigue had the biggest impact on the respondent's ability to maintain employment. Other symptoms that caused difficulty when at work included cognitive changes, stress and anxiety, reduced dexterity, changes to posture and mobility. A lack of flexibility by employers was noted to contribute to difficulty in work. Particular work roles were identified by respondents as being more problematic than others such as dealing with customers or speaking in public, often causing their symptoms of anxiety or tremor to be exacerbated.

The respondents in this study lost an average of 13.5 years of employment, and left work around 3 years following the receipt of their diagnosis. Respondents acknowledged the impact of their loss of employment on their health and well-being. In

particular, they felt that giving up work would, and has, contributed to a social withdrawal. Respondents identified that employment gave them mental stimulation and they valued the sense of identity, and self esteem, that being in employment gave to them. They also identified the financial need to work to support their chosen lifestyle.

The collected data highlighted a lack of information and support to help people with PD maintain employment. It was interesting to note that few people actively sought help to maintain employment, and, considered that leaving work was a fait accompli and didn't believe that anything could be done to prevent it happening. Some had received advice from doctors or occupational health personnel to give up work. Those respondents who had sought help rarely found useful sources of support other than the PDS, and the respondent's awareness of employment rights was poor. The results indicated that interaction with non-specialist professionals, in relation to the maintenance of work, was ineffective.

This study considered the impact that maintaining, or relinquishing, employment had on other aspects of the person with PD life. Results indicated that for some people, managing to remain in employment left them with very little energy to maintain their leisure and social activities. However, when they did leave work, the types of leisure and social activities changed to solitary and sedentary ones. The results indicated a need for support to consider how to stay in employment, but also, how to make a positive decision about leaving, taking into account the impact that staying might have on fatigue, and ability to fully engage in other aspects of daily living. In addition, the results highlight the importance of assisting the individual to maintain, and build, their lifestyle outside of the work situation, to develop an identity that does not disappear when employment is lost.

6.10 Finalising validation

The validation of the construction of the study, and the methods used to collect data, has been discussed in sections 3.6 and 4.6, however, the validation of the intervention described in this chapter, requires consideration.

The first aspect to consider is validation of the interpretation of results. Transforming the results into an intervention was an inventive and creative approach but not without risk of a personal view of the data. However initial validation of this approach was highlighted by the participants identifying the need for and the lack of this type of

intervention. Further validation was carried out by the steering group who confirmed the necessity of a staged approach to an intervention. The intervention was then presented to clinicians in two forums, firstly as part of an invited presentation to the Multi-Disciplinary Conference 'From Science to Practice' hosted by the Royal College of Physicians and secondly as a paper presentation at the College of Occupational Therapists Annual Conference (2007). On both of these occasions the process undertaken to construct the intervention was made explicit along with the content of the intervention. The feedback from occupational therapists and other clinicians was extremely positive. They confirmed the current lack of support for younger people with neurological conditions who wish to maintain their employment and the need for a specific intervention to be delivered by clinicians with specialist knowledge of neurological conditions. Occupational therapists reported that this intervention sat comfortably within their approach and was exciting and challenging to their current practice. Occupational therapists from other clinical areas such as mental health recognised that this intervention could be transferred and utilised with their client groups.

The final validation of the intervention was carried out in practice. Frequently adults of working age with neurological conditions who have employment related difficulties are referred to the researcher. Following the validation of the intervention with clinicians the intervention was tested in practice with two people referred to the researcher. In this instance the sequence of the stages of the intervention were considered in addition to the content. This practice based testing confirmed that the staged approach to the intervention was appropriate.

7 Discussion, Conclusion and Recommendations

7.1 Discussion

In this chapter a final consideration of the research aims will be presented alongside the key messages highlighted by the employment experience of younger people with PD. These key messages include; the need to ensure that the maintenance of employment is considered and then supported by the health professionals that the individual with PD comes into contact with, the need for specific intervention to support the maintenance of employment to be carried out by a specialist occupational therapist, for this intervention to enable a change or reconstruction of a narrative, which could then alter the trajectory of the withdrawal from work and other activities. The limitations of this study have been identified throughout the document as the research process has been described. However, in this chapter, the limitations relating to each aspect of the study have been assembled and will be considered collectively. Finally, in this chapter, to ensure that the results continue to be explored post submission of the thesis, an evaluation strategy, using a contemporary model for trialling complex interventions, will be offered.

The aims of this study were:

1) To understand the employment experience and trajectory of younger people with PD.

2) To model an intervention to maintain employment.

To achieve these aims the following objectives were set:

i) Explore the meaning of occupation for younger people with PD

ii) Identify the aspects of work that may be beneficial to someone with PD

iii) Understand the strategies used for maintaining work by people with PD

iv) Appreciate the decision making process utilized by younger people with PD when choosing to remain in or leave work

The aims of the study have been achieved though collecting the employment experience of a large number of younger people with PD, using a variety of methods, within an overall interpretative methodology. The meaning of occupation and the benefits of employment were identified. Participants felt that employment was beneficial in many ways to help them to manage their symptoms, and that losing employment had a

negative impact on their self-identity. The barriers to employment were identified, some of these were due to specific symptoms, others, were environmental and attitudinal. The strategies engaged by younger people with PD to overcome these barriers were discovered, which included taking a partnership approach with their employer, problem solving, and attitude change. The factors that are of importance to younger people with PD when making their decision to remain in or leave work have been acknowledged, such as consideration of their work-life balance, and other occupational roles. Participants identified the need for targeted assistance to support them in trying to maintain their employment or to assist with making an informed decision to leave employment. The assistance was described in this study in the form of a seven stage intervention which was validated both with clinicians and in practice.

7.1.1 A team approach to measuring outcomes using participation

The respondents in this study highlighted the lack of attention paid to their employment difficulties by medical staff, and this reflected the findings of the examined literature. In the researcher's clinical experience, this deficiency is due to the emphasis placed on symptom management, and the emphasis of measuring symptom management within an impairment domain. Currently measuring the impact of medical and Allied Health Professions intervention usually occurs within an impairment domain. Often a younger person with a neurological condition only comes into contact with services when he/she has an appointment with his/her consultant neurologist or GP and during these consultations, the focus is on symptom management. However, as indicated by the results of this study, younger people with PD have many life roles and responsibilities, including employment, and the impact of their condition on these roles and responsibilities is of paramount importance to them. Symptoms, and the disabilities caused by those symptoms, need to be considered within the context of a person's life. It is therefore proposed, that the effectiveness of interventions, should be measured at the level of 'participation' as described by the International Classification of Functioning, Disability and Health (WHO 2001). Younger people with PD, who may be considered by medical staff to have minor symptoms, may have to make major life changes during this period, including relinquishing their employment. If questions are asked about participation activities such as employment, then, people with neurological conditions are more likely to view the maintenance of these activities as important i.e. considering participation, rather than symptoms. Emphasis at this point therefore may

be on education and support and promoting choice regarding the management of this condition. A focus on participation could create a framework for a multi-disciplinary approach to PD and other progressive neurological conditions. Symptoms should be targeted by the multi-disciplinary team depending on the level of interference they cause with an individual's life roles, and, by asking questions such as *'What do you need to be able to do?'* and approaching those difficulties in partnership with the individual. The specific symptoms that cause difficulties with employment highlighted in this study are apathy, depression, fatigue and anxiety. The impact of these symptoms on an individual's ability to maintain their employment should be examined with a greater emphasis on the assessment, medical management and non-medical management than is currently the practice.

Often, dealing with employment is the first major difficulty encountered for younger people with PD, and how they deal with this can act, not only as a metaphor for dealing with future difficulties, but can establish a sense of mastery over the condition. In this study, participants have identified the benefits of staying in employment, and these benefits of maintaining participation could have a direct impact at an impairment level. Staying in work may prevent some of the associated symptoms of PD such as depression, and therefore, maintenance of these roles can function as an outcome to be measured and valued. The intervention presented in chapter five focuses on participation as an outcome, either in employment or via a successful withdrawal from employment to a range of beneficial activities. This intervention could be part of a range of interventions offered by a participation focused multi-disciplinary team.

7.1.2 Employment intervention delivered by occupational therapists

The respondents in the study have identified that an intervention to assist them to maintain employment is not currently available. This is reflected in the literature, which highlights a lack of interagency working, a focus on people who are currently unemployed, and interventions provided by non-specialists. The intervention presented in chapter five must be implemented by a professional with a specialist knowledge of PD, and, as indicated by the examined literature and by the researcher's experience, should be delivered by an occupational therapist with PD specialist knowledge and skills. OT improves occupational performance by improving skills knowledge and attitudes (Jain et al 2005). The intervention described in this study improves

occupational performance by providing intervention at a skill level to enhance performance, at knowledge level to support performance and at attitude level to change performance. For example a person with PD might improve their skills in fatigue and anxiety management, improve their knowledge of how to adapt work related tasks or where to seek support, and change their attitude towards their condition by gaining a sense of mastery, and feeling less like a victim of circumstances. Occupational therapists have four main roles in the management of PD: problem solver, educator, networker and supporter (Deane et al 2003c). The intervention proposed in this study fulfils all of these roles, for example identifying the specific work related tasks that are causing difficulty and applying solutions to tackle those problems, educating the person with PD, their colleagues or their employer regarding the condition and its work related impact, identifying and working with appropriate personnel to support the person with PD in their work and finally providing advocacy in employer-employee meetings. Working within an MDT, the occupational therapist could provide the described intervention, but involve members of the MDT when necessary, with the focus being on maintaining participation.

7.1.3 Reconstructing a narrative construct of identity

The narrative construct of identity related to employment has been identified in this study. The challenges to this identity are many. Firstly, as PD is a progressive condition, the context is constantly changing, and it is difficult for the person with PD to continually re-construct their identity. In this case, for some, it may be easier to leave work and make the context stable, rather than constantly having to adapt in the workplace. There is also the issue of the biographical structuring of identity if someone leaves work. Rather than being identified by their career or work role, they become 'someone with PD'. It is important to consider their status in this transition, if someone is separated from their work role identity, then, to where are they incorporated? If they leave work due to ill-health then they become 'disabled' rather than 'retired'. Employment is a 'legitimate' identity, and the social change brought about by leaving employment will mean that the person needs to construct their identity again, redefining themselves in society, rather than becoming socially excluded. Luckily, in our society, there is ample scope for people to reconstruct themselves. Within employment, the 'job for life' expectation has disappeared, and most people expect to work in a variety of

settings and roles during the course of their life, and, accept periods of time out of work, particularly within the current economic climate.

The narrative expressed by the participants was used to guide the first stage of the intervention:

'I can't do my job and I have to leave'.

The intervention aims to change the narrative of the individual to:

"I have strategies that will enable me to remain in work and respond to changes in my condition now and in the future".

This change of narrative, can then alter the trajectory of the employment experience, from a perceived premature and forced retirement, to, the maintenance of work. The intervention proposed in this study, can enable an individual to remain in employment or, for an exit strategy to be developed by the person with PD. This exit strategy will incorporate an informed decision to leave work, and the construction of a new identity through engagement in beneficial activities.

7.1.4 Reflection on the research process

Undertaking this study has taken me from a position of a practitioner of occupational therapy, through a temporary and transitionary period of being a researcher to becoming a research informed practitioner. This study was initially designed to investigate the key research aims and the grant conditions required a concrete outcome to be produced for the funding providers. However, the added-value of engaging in this research project is that it has allowed my own practice to develop throughout the course of the study in three distinct ways.

Firstly, and most obviously, the results have transformed my clinical practice with people who have PD through the creation and application of an evidence-based intervention which reflects the philosophy of my profession and utilises the range of techniques applied by occupational therapists. I understand the importance of each stage of the intervention and the consideration of the wider aspects and impact of employment in someone's life. This intervention enables me to tackle the employment issues of people with PD with confidence and in a systematic way and I can observe the value of the intervention for the individuals receiving it.

Secondly, the process of engaging in this study has altered the way in which I approach practice, co-producing research with people who have PD, has given me a detailed insight into the lived experience of this condition with a specific focus on the issues that are of importance to working age adults. This insight, in addition to an in-depth knowledge of current evidence, has illuminated the proliferation of contemporary legislation relating to people with neurological conditions and has enabled me to confidently influence regional service developments for this group. When considering service developments I now understand how useful co-production of these developments is to ensure that the needs of people with long term neurological conditions are met. I have reflected on how poor user-involvement has been previously in my service, at best tokenistic and I am now influencing my service to engage users more effectively in service design.

Thirdly, I now approach practice having utilised and critiqued the available evidence. I have developed skills in searching widely for evidence that is relevant to a particular area of practice when there is no specific evidence for that practice available. I value the impact that having knowledge of the evidence-base has on my practice with people with long-term neurological conditions and the importance of spending time considering the evidence. I can now confidently justify this practice when it is challenged within the current culture in the health service which often only recognises the importance of 'face to face' time.

This journey from practitioner to research-informed practitioner has influenced my practice positively, changing the way in which I approach practice, engage with and learn from people who use my service and utilise and challenge existing practice. The process has been of immense value to myself, the service I work in and for the people who use my service.

7.1.5 Limitations

7.1.5.1 Bias of sample

A limitation of the study was the difficulty in accessing the target population of younger people with PD. There are no national registers of people with PD and there is no single service pathway to enable access to potential participants via their medical practitioner. Utilising the PDS to access participants was an obvious choice, however, it was acknowledged that this would only capture people who were registered with the PDS

and not the whole population of younger people with PD in England. Through discussions with the PDS it was decided to utilise the PDNS to access participants for the initial data collection method. The PDS has a register of all the PDNS in the UK. The case-loads of the PDNS contain people who have registered with the PDS and those who have no contact with the society. However, whilst using the PDNS to distribute the questionnaires should have enabled distribution to a wide selection of people with PD, this method was not as successful as anticipated. This could have been either due to the busy workload that the PDNS have or due to another project relating to employment already having used this network to distribute questionnaires. In retrospect it may have been more successful to have used the PDS member's network, which although would have created a bias, should have resulted in a higher response rate.

7.1.5.2 Data collection

Of the three methods of data collection used in this study, the first method (questionnaire) is the one which, in retrospect, could have had an improved delivery. The questionnaire was carefully considered and developed with the steering group, the questions and layout were appropriate and gathered valuable data however, as previously described the postal version did not yield a high return which could have been due to distribution difficulties. An on-line version of the questionnaire was developed when it was discovered the response rate to the postal questionnaire was low, and this should have been available from the onset in addition to the postal questionnaire.

7.1.5.3 Practitioner bias

It is acknowledged that due to the amount of experience and the length of time that the researcher has spent working as a practitioner with people who have PD, there may be deeply ingrained assumptions and pre-conceptions held by the researcher that could have created a weighting or bias when the results were considered. It was a concern that the researcher's view of reality could be tangential to that of the social constructs formed by the participants. However, any researcher bias has been explored through the validation process with other practitioners (see section 5.10), through the use of co-production, and through the interpretation of results being made as transparent as possible in the research process. User involvement in each stage has ensured that a

range of individuals' voices have been heard and a range of results produced and transparency in the process will enable individuals to recognise similarities in their own experience. This research has been carried out in the PD population, however, the presentation of the results through in-depth description should enable decisions by readers about the potential for transfer and perhaps testing of the model in other populations with similar issues.

7.1.5.4 Co-production

It was the intention of the researcher to co-produce this research project with service users. The Steering Group was an invaluable resource in terms of information, support and ensuring that the project remained grounded and reflected the needs of younger people with PD. Close liaison with the Community Services Manager at the PDS enabled the project to develop in line with the current policies and directives that the PDS had for younger people. Attendance at events held by the PDS (YAPMEET etc) facilitated contact with a wide group of younger people with PD, PDS staff and statutory services staff to discuss the project, validate outcomes and remain updated with current developments within the Society. Working with an organisation did, in some respects, give easier access to the research population but, in this case, relying on the organisation meant that every stage of the data collection process was delayed in some way. This was often due to agreements not being passed onto others within the organisation or the staff member leaving. The organisation embarked on some major restructuring just following the start of this research project which was responsible for the difficulties encountered.

7.2 Conclusion

The thesis has contributed to knowledge and practice through the development and testing of a seven stage occupational therapy intervention for young people with PD. This intervention will facilitate the maintenance of employment as a vehicle to promote health for people with PD. The intervention demonstrates the importance of targeted and specialist assistance for people with PD, and encourages informed choice about options available regarding employment, and provides the information and support to make those choices. The intervention should be delivered by an occupational therapist with specialist skills and knowledge working within a multi-disciplinary team. At this

point, the intervention has not yet been evaluated, and such an evaluation would form the basis for post-doctoral study.

7.3   Recommendations

It is recommended that the intervention described in this study should be implemented and evaluated. In order to evaluate the effectiveness of this intervention, it will need to be trialled, but trialling a multi-faceted intervention is challenging. The Medical Research Council (MRC) has highlighted the challenges of defining, and subsequently trialling, complex interventions, such as the staged intervention for the maintenance of employment described in this study (Campbell et al 2000). They recognise defining, developing, documenting, and reproducing complex interventions as being an intricate process and propose an iterative phased approach to the development and evaluation of non-pharmacological interventions to improve the generalisability of results. The MRC acknowledge that the evaluation of complex interventions requires the use of both quantitative and qualitative methods.

The first phase of the process described by the MRC is to define the component parts of the intervention and their interrelationships. Descriptive investigations and qualitative methods such as focus groups or surveys are suggested to identify and understand the relevant components, how the intervention works, and potential barriers. The second phase described by the MRC identifies the optimum form of the intervention in terms of the timing, duration and intensity. It is in this second phase, that the trial is designed, including a pilot, or exploratory trial, and consideration of the need for a control group and appropriate outcome measures. Phase three addresses the methodological issues and phase four examines how the complex intervention has been adopted by, or changed practice.

This process for evaluating complex, non-pharmacological interventions would be appropriate for evaluating the staged intervention for the maintenance of employment described in this study. Phase one of the evaluation process has already been completed, with the component parts of the intervention identified and described. Elements of phase two have been accomplished with the intervention being trialled in practice by the researcher. However, to complete a formal trial of this intervention, further work needs to be done to consider firstly, the timing of the intervention. How soon following diagnosis should the intervention commence? There is a benefit to starting the

intervention sooner rather than later in the disease progression, however, this may not be the time when the person with PD is receptive. The person may prefer to have the intervention commence only when they begin to experience problems at work, and are considering leaving. The intervention is an iterative process and can be returned to in the future, therefore, should only the first experience of the intervention be evaluated? Secondly the intensity of the intervention should be considered. How long should be left between the stages of the intervention? Could two or more of the stages be 'rolled together' within a session? Can there be a standard intensity or should this be dictated by the person with PD? Thirdly, the duration of the intervention requires deliberation. This will also involve service issues and cost implications. How long can be spent providing this intervention? How much does this intervention cost? Other factors also need to be considered, such as location of the intervention and who it will be provided by, with the related training needs. Finally, appropriate outcome measures should be identified. The main aim of this intervention is the maintenance of employment for longer than if the intervention had not been applied. The related aim is for the person with PD to feel like they have made an informed choice to leave or stay in employment, adoption of beneficial activities to replace employment and development of a transferable coping strategy. Trying to capture these important outcomes will be challenging, but all of these factors will need to be identified in order for an effective trial to take place.

8   References

Aas, R.W. and Grotle, M. (2007). "Client's using community occupational therapy services: sociodemographic factors and the occurrence of diseases and disabilities." Scandinavian Journal of Occupational Therapy **14** (3): 150-159.

Arnstein, S R (1969) "A Ladder of Citizen Participation." JAIP, **35** (4): 216-224.

Backer, J. (2006). "The Symptom Experience of Patients With Parkinson's Disease." The Journal of Neuroscience Nursing **38**(1): 51-57.

Banks, P. and M. Lawrence (2006). "The Disability Discrimination Act, a necessary, but not sufficient safeguard for people with progressive conditions in the workplace? The experiences of younger people with Parkinson's Disease." Disability and Rehabilitation **28**(1): 13-24.

Barnes, C. (1990). Cabbage Syndrome The Social Construction of Dependence. Basingstoke, The Falmer Press.

Bhatia, K., D. Brooks, et al. (2001). "Updated guidelines for the managements of Parkinson's disease." Hospital Medicine **62**(2): 456 - 70.

Bhatia, S. and Gupta, A. (2003). "Impairments in activities of daily living in Parkinson's disease: Implications for management." Neurorehabilitation **18** 209 - 214

Birleson, A. (2002). "Parkinson's disease and younger people: impact on activities." British Journal of Therapy and Rehabilitation **9**(12): 466 - 471.

Black, C. (2008). Working for a Healthier Tomorrow, Crown.

Blaikie, N. W. H. (1991). "A critique of the use of triangulation in social research." Quality and Quantity **25**: 115-136.

Borek, L. L., R. Kohn, et al. (2006). "Mood and sleep in Parkinson's." Journal of Clinical Psychiatry **67**(6): 958-963.

Bowling, A. (1997). Research Methods in Health. Buckingham, Open University Press.

British Society of Rehabilitation Medicine, (2000). "Vocational Rehabilitation: The Way Forward." London, Royal College of Physicians

British Society of Rehabilitation Medicine. (2004). "Vocational assessment and rehabilitation after acquired brain injury." London, Royal College of Physicians.

Brod, M., G. Mendelsohn, et al. (1998). "Patients experiences of Parkinson's disease." Journal of Gerontology **53B**(4): 213-22.

Brosse, A. L., E. S. Sheets, et al. (2002). "Exercise and the Treatment of Clinical Depression in Adults: Recent Findings and Future Directions." Sports Medicine **32**(12): 741-760.

Brown, R. I. (1997). Quality of Life for People with Disabilities. Cheltenham, Stanley Thornes.

Burchardt, T. (2002). Enduring economic exclusion: disabled people, income and work, www.jrf.org.uk/knowledge/findings/socialpolicy/060.asp.

Burn, D. J. (2002). "Beyond the Iron Mask: Towards Better Recognition and Treatment of Depression Associated with Parkinson's Disease." Movement Disorders **17**(3): 445 - 454.

Burr, V. (1995). An Introduction to Social Construction. London, Routledge.

Calne, D. and J. Langston (1983). "Aetiology of Parkinson's disease." The Lancet **322**(8365-8366): 1457-1459.

Calne, S. M., S. C. Lidstone, et al. (2008). "Psychosocial issues in young-onset Parkinson's disease: Current research and challenges." Parkinsonism & Related Disorders **14**(2): 143-150.

Campbell, J. T., R. L. Daft, et al. (1982). What to study: generating and developing research questions. London, Sage.

Campbell, M., R. Fitzpatrick, et al. (2000). "Framework for design and evaluation of complex interventions to improve health." British Medical Journal **321**(16 September): 694-696.

Chesson, R., D. Cockhead, et al. (1996). Availability of Therapy Services to People with Parkinson's Disease Living in the Community. Edinburgh, Robert Gordon University.

Chesson, R., D. Cockhead, et al. (1999). "Expert opinion on therapy for people with Parkinson's disease." British Journal of Therapy and Rehabilitation 60(3): 124-29.

Cicerone, K., C. Dahlberg, et al. (2000). "Evidence-based cognitive rehabilitation: recommendations for clinical practice." Archives of Physical Medicine & Rehabilitation 81(12): 1596-1615.

Cicourel, A. (1973). Cognitive Sociology. Harmondsworth, Penguin.

Clarke, C. (2001). Parkinson's Disease in Practice. London, Royal Society of Medicine Press.

Clarke, C. E., A. Furmston, et al. (2009). "Pilot randomised controlled trial of occupational therapy to optimise independence in Parkinson's disease: the PD OT trial." Journal of Neurology, Neurosurgery & Psychiatry 80(9): 976-8.

Clarke, C. E., R. M. Zobkiw, et al. (1995). "Quality of life and care in Parkinson's disease." British Journal of Clinical Practise 49(6): 288-293.

College of Occupational Therapists (2008). The College of Occupational Therapists Vocational Rehabilitation Strategy. London, College of Occupational Therapists.

Creswell, J. W. (2003). Research Design. London, Sage.

Crizzle, A. and I. Newhouse (2006). "Is physical exercise beneficial for persons with Parkinson's disease?" Clinical Journal of Sports Medicine 16(5): 422-425.

Cronin-Golomb, A., S. Corkin, et al. (1994). "Impaired problem solving in Parkinson's disease: impact of a set-shifting deficit." Neuropsychologia. 32(5): 579-93.

De Boer, A., M. Sprangers, et al. (1999). "Predictors of health care use in patients with Parkinson's disease: a longitudinal study." Movement Disorders 14(5): 772-79.

Deane, K., C. Ellis-Hill, et al. (2001). "Occupational Therapy for Parkinson's Disease." The cochrane library ID #CD002813.

Deane, K. H. O., C. Ellis-Hill, et al. (2003b). "A Survey of Current Occupational Therapy Practice for Parkinson's Disease in the United Kingdom." British Journal of Occupational Therapy **66**(5): 193 - 200.

Deane, K. H. O., C. Ellis-Hill, et al. (2003c). "A Delphi Survey of Best Practice Occupational Therapy for Parkinson's Disease in the United Kingdom." British Journal of Occupational Therapy **66**(6): 247 - 254.

Deane, K. H. O., R. Whurr, et al. (2003a). Speech and language therapy versus placebo or no intervention for dysarthria in Parkinson's disease (Cochrane Review). Oxford, The Cochrane Library**:** Issue 3.

De Angelis, E. C., Mourao, L.F. et al. (1997). "Effect of voice rehabilitation on oral communication of Parkinson's disease patients." Acta Neurologica Scandinavica **96**(4): 199-205.

Denzin, N. K. (1989). Interpretive Interactionism. Newbury Park, Sage.

Denzin, N. K. and Y. S. Lincoln (1998). The Landscape of Qualitative Research. London, Sage Publications.

Denzin, N. K. and Y. S. Lincoln (2003). Strategies of Qualitative Inquiry. London, Sage.

Dixon, L., D. Duncan, et al. (2007). Occupational therapy for patients with Parkinson's disease. Oxford, Cochrane Database of Systematic Reviews.

Department of Health. (1998) Research—What's in it for Consumers? Report of the Standing Advisory Committee on Consumer Involvement in the NHS Research & Development Programme. London: Department of Health.

Department of Health. (2000a) Working Partnerships. Consumers in Research Third Annual Report. London: Department of Health.

Department of Health (2000b). Research and Development for a First Class Service. London: Department of Health.

Department of Health (2001b). The Expert Patient: A new approach to chronic disease management. London: Department of Health.

Department of Health (2001a). Making it work: inspection of welfare to work for disabled people. London: Department of Health.

Department of Health (2005a). National Service Framework for Long Term Conditions. London: Department of Health.

Department of Health (2005b). Research Governance Framework for Health and Social Care. London: Department of Health.

Department of Justice (2004). Disability Bill. London

Department of Social Security (1998). New Ambitions for Our Country: A New Contract for Welfare. London: Stationary Office

Department of Work and Pensions (1995). Disability Discrimination Act. London: HMSO

Department of Work and Pensions (2006). A new deal for welfare: empowering people to work. London, Department of work and pensions.

Department of Work and Pensions and Department of Health (2008). Improving Health and Work: Changing lives. London, Department of Health, Department of Work and Pensions and the Health and Safety Executive.

Doherty, K. (1991). The impact of Parkinson's disease on families. Conference of People in the Caring Professions: Working with Families, Melbourne, Australia, NAPA Bulletin issue 2.

Drummond, A. (1996). Research Methods for Therapists. London, Chapman&Hall.

Ehman, T., R. Beninger, et al. (1990). "Coping, social support and depressive symptoms in Parkinson's disease." Journal of Geriatric Psychiatry and Neurology **3**: 85-90.

Ehrt, U. and D. Aarsland (2005). "Psychiatric aspects of Parkinson's disease." Current Opinion in Psychiatry **18**(3): 335-341.

Ellgring, H., S. Seiler, et al. (1990). Psychosocial problems of Parkinson patients: approaches to assessment to treatment. Advances in Neurology. Parkinson's Disease: Anatomy, Pathology and Treatment. Streifler MB, Korczyn AD, Melamed E and Youdim MBH. New York, Raven Press. **53:** 349-53.

Ellgring, H., S. Seiler, et al. (1993). "Psychosocial aspects of Parkinson's disease." Neurology **43 (suppl 6)**: S41-44.

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Elsworth, C., H. Dawes, et al. (2009). "A study of perceived facilitators to physical activity in neurological conditions." International Journal of Therapy and Rehabilitation **16**(1): 17-24.

EPDA Plus (2008). "Counting the Cost," EPDAPLUS Spring 2008 (7) 20-21

Erdal, K. J. (2001). "Depression and anxiety in person's with Parkinson's disease with and without "on-off" phenomena." Journal of Clinical Psychology in Medical Settings **8**(4): 293-299.

Fahn, S. (1995). "The freezing phenomenon in Parkinsonism." Advances in Neurology **67**(53-63).

Fahn, S. (2008). "How do you treat motor complications in Parkinson's disease: Medicine, surgery, or both?" Annals of Neurology, **62**(Supplement 2): S56-S64.

Feeney, F., S. Egan, et al. (2005). "Treatment of depression and anxiety in Parkinson's Disease: A pilot study usung group cognitive behavioural therapy." Clinical Psychologist **9**(1): 31-38.

Fenech, A. (2008). "The benefits and barriers to leisure occupations." NeuroRehabilitation, **23**(4): 295-297.

Ferraz, H. B. and V. Borges (2002). "Parkinson's disease." Revista Brasileira de Medicina **59**(4): 207-219.

Fraser, R. T., D. C. Clemmons, et al. (2003). "Vocational Rehabilitation in Multiple Sclerosis: A profile of clients seeking services." Work **21**: 69-76.

Friedman, J. H. and H. Friedman (2001). "Fatigue in Parkinson's Disease: a nine-year follow up." Movement Disorders **16**(6): 1120-1122.

Fuchs, G. A. (2003). "The relevance efficacy of speech therapy, occupational therapy and physiotherapy in Parkinson's disease." Aktuelle Neurologie **30**(2): S246-S248.

Gage, H. and L. Storey (2004). "Rehabilitation for Parkinson's disease: A systematic review of available evidence." Clinical Rehabilitation **18**(5): 463-482.

Gaudet, P. (2002). "Measuring the impact of Parkinson's disease: An occupational therapy perspective." Canadian Journal of Occupational Therapy **69**(2): 104-113.

Ghazi-Noori, S., T. H. Chung, et al. (2003). Therapies for Depression in Parkinson's Disease (Cochrane Review). Oxford, The Cochrane Library.

Gibb, W. and A. Lees (1988). "The relevance of the lewy boby to the pathogenesis of idiopathic Parkinson's disease." Journal of Neurology, Neurosurgery & Psychiatry **51**: 745-752.

Gillen, G. (2000). Maximising independence: Occupational Therapy intervention for patients with Parkinson's Disease. Parkinson's Disease and Quality of Life. L. Cote, L. Spinzeles, R. Elliott and H. Kutscher. London New York, Haworth Press.

Goodare H, Lockwood S. (1999) "Involving patients in clinical research". British Medical Journal. 319: 724-725

Gordy, M. (1996). Social Support and Medical Care, http://www.hon.ch/Library/papers/GORDY.htm. Accessed **2001**.

Hagell, P. and L. Brundin (2009). "Towards an understanding of fatigue in Parkinson's disease." Journal of Neurology, Neurosurgery and Psychiatry

Hanley B, Truesdale A, King A, Elbourne D, Chalmers I. (2001) "Involving consumers in designing, conducting, and interpreting randomized controlled trials: questionnaire survey". British Medical Journal **322**: 519–523

Hantz, P., G. Caradoc-Davies, et al. (1994). "Depression in Parkinson's disease." American Journal of Psychiatry **151**(7): 1010-14.

Havlikova, E., J. P. v. Dijk, et al. (2008a). "Fatigue in Parkinson's disease is not relates to excessive sleepiness or quality of sleep." journal of Neurological Sciences **270**(1-2): 107-113.

Havlikova, E., J. Rosenberger, et al. (2008b). "Clinical and psychological factors associated wtih fatigue in patients with Parkinson's disease." Parkinsonism & Related Disorders **14**(3): 187-192.

Heberlein, I. and P. Vieregge (2005). "The influence of speech disturbances on quality of life and coping strategies of Parkinson's disease patients [German]." Forum Logopadie **19**(3): 26-31.

Hobson, P. and J. Meara (1999). "The detection of dementia and cognitive impairment in a community population of elderly people with Parkinson's disease by use of the CAMCOG neuropsychological test." Age and Ageing **28**: 39-43.

Ishihara, L. and C. Brayne (2006). "A systematic review of depression and mental illness preceign Parkinson's disease." Acta Neurologica Scandinavica **113**(4): 211-220.

Jackson, G. and A. Kelsey (1999). "The needs of neurology patients after discharge." Professional Nurse **14**(7): 467-70.

Jahanshahi and C. D. Marsden. London, Souvenir Press**:** 181 - 201.

Jain, N. B., M. Sullivan, et al. (2007). "Factors associated with health-related quality of life in chronic spinal cord injury." American Journal of Physical Medicine & Rehabilitation, **86**(5): 387-96.

Jankovic (1987). Pathophysiology and motor symptoms. Handbook of Parkinson's Disease. K. Koller.

Jankovic, J. (2000). "Parkinson's disease therapy: Tailoring choices for early and late disease, young and old patients." Clinical Neuropharmacology **23**(5): 252-261.

Jenkinson, C., R. Fitzpatrick, et al. (1999). "Health-Related Quality-of-Life Measurements in Patients with Parkinson's Disease." Pharmacoeconomics **15**(2): 157 - 165.

Jick, T. D. (1979). "Mixing Qualitative and Quantitative Methods: Triangulation in Action." Administrative Science Quarterly **24**(4): 602-611.

Johnson, K. L., D. Amtmann, et al. (2004). "Medical, psychological, social and pragmatic barriers to employment for people with Multiple Sclerosis." Journal of Rehabilitation **70**(1): 38-41.

Karlsen, K. H., E. Tandberg, et al. (2000). "Health Related Quality of Life in Parkinson's Disease: A Prospective Longitudinal Study." Journal of Neurosurgery and Psychiatry **69**(584-589).

Khan, F., L. Ng, et al. (2009). Effectiveness of vocational rehabilitation intervention on the return to work and employment of persons with Multiple Sclerosis, Cochrane Institute of Systematic Reviews.

Klepac, N., V. Trkulja, et al. (2008). "Is quality of life in non-demented Parkinson's Disease patients related to cognitive performance? A clinic-based cross-sectional study." European Journal of Neurology **15**: 128-133.

Koplas, P., H. Gans, et al. (1999). "Quality of life and Parkinson's disease." Journal of Gerontology **54A**(4): M197-M202.

Kosma, M., B. Cardinal, et al. (2004). "Predictors of physical activity stage of change among adults with physical disabilities." American Journal of Health Promotion **19**(2): 114-117.

Kostic, V., S. Filipovic, et al. (1994). "Effect of age at onset on frequency of depression in Parkinson's disease." Journal of Neurology, Neurosurgery and Psychiatry **57**(10): 1265-67.

Kyle, J. (1993). Depression. Parkinson's Disease Society of Greater Washington Magazine.

Law M, S. Baptiste, et al. (1998). Canadian Occupational Performance Measure. Ottowa, CAOT Publications.

Lees, F., P. Clark, et al. (2005). "Barriers to exercise behavior among older adults: A focus-group study." Journal of Aging and Physical Activity **13**: 23-33.

Lewis, D. (1999). "Computer based approached to patient education: a review of the literature." Journal of the American Medical Informatics Association **6**(4): 272 - 82.

Lorenzen, H. (2008). "Adaptation - Participation and quality of life through successful adaptation to altered living conditions." Ergotherapie und Rehabilitation **47**(8): 19-24.

Lundervold, D. A., R. Pahwa, et al. (2009). "Effect og behavioural intervention on comorbid general anxiety disorder and Parkinson's disease." The Journal of Aging and Mental Health **32**(1): 104-117.

Macedo, A. M., S. P. Oakley, et al. (2009). "Functional and work outcomes improve in patients with rheumatiod arthritis who receive targeted, comprehensive occupational therapy."

Macmahon, D. (2000). "Parkinson's: integrating the primary and secondary care guideline." Practitioner **244**(1609): 370 - 378.

Marsden C.D., and Parkes, J.D. (1976). ""On-off" effects in patients with Parkinson's disease on chronic levodopa therapy." The Lancet **7**(7954): 292-296.

Marsh, L. (2000). "Anxiety disorders in Parkinson's disease." Interntational Review of Psychiatry **12**(4): 307-318.

Marshall, C. and G. Rossman (1995). Designing Qualitative Research. London, Sage Publications.

Martikainen, K. K., T. H. Luukkaala, et al. (2006). "Parkinson's disease and working capacity." Movement Disorders **21**(12): 2187-2191.

Martin, C. and D. Thompson (2001). " Does dialysis adequacy impact on the quality of life of end-stage renal disease patients?" Clinical Effectiveness in Nursing **5**(2): 57-65.

Mathison, S. (1988). "Why Triangulate." Educational Researcher **17**(2): 13-17.

McCabe, M.P., Roberts, C. and Firth, L. (2008) "Work and recreational changes among people with neurological illness and their caregivers." Disability and Rehabilitation **30**(8): 600 - 10

McCrone, P., M. Heslin, et al. (2008). "Multiple sclerosis in the UK: service use, costs, quality of life and disability." Pharmacoeconomics, **26**(10): 847-60.

McNamara, P. and R. Durso (2003). "Pragmatic communication skills in patients with Parkinson's disease." Brain and Language **84**(3): 414-423.

McNamara, P., R. Durso, et al. (2003). "Counterfactual cognitive deficit in persons with Parkinson's disease." Journal of Neurology, Neurosurgery and Psychiatry **74**(8): 1065-70.

McNamara, P., R. Durso, et al. (2006). "Life goals of patients with Parkinson's disease:a pilot study on correlations with mood and cognitive functions." Clinical Rehabilitation **20**: 818-826.

Menza, M. and R. Dobkin (2005). "Anxiety and Parkinson's Disease." <u>Primary Psychiatry</u> **12**(7): 63-68.

Miller, N., E. Noble, et al. (2006). "Life with communication changes in Parkinson's disease." <u>Age and Ageing</u> **35**(235-239).

Miller, S.D. Hubble, M.A. Duncan, B.L.(1996) "Handbook of Solution-focused brief therapy". San Francisco, Jossey-Bass Publishers

Mondolo, F., M. Jahanshahi, et al. (2007). "Evaluation of anxiety in PArkinson's disease with some commonly used rating scales." <u>Neurological Sciences</u> **28**(5): 270-275.

Morgan, D. L. (1993). <u>Successful Focus Groups</u>. Newbury Park, Sage Publications.

Morris, J. (2003). Improving Support for Younger People Locally

Report on findings from younger people's events 2003. London, Parkinson's Disease Society.

Musick, M. A. and J. Wilson (2003). "Volunteering and depression: the role of psychological and social resources in different age groups." <u>Social Science and Medicine</u> **56**(2): 259-269.

Mutch, W., A. Strudwick, et al. (1986). "Parkinson's disease: disability, review and management." <u>British Medical Journal</u> **293**: 675-77.

Nieuwboer, A., R. Dom, et al. (2004). "lectromyographic profiles of gait prior to onset of freezing episodes in patients with Parkinson's disease." <u>Brain</u> **127**: 1650-1660.

Nijhof, G. (1995). "Parkinson's disease as a problem of shame in public appearance." <u>Sociology of Health and Illness</u> **17**(2): 193-205.

Nijkrake, M. J., S. H. Keus, et al. (2009). "Allied health care in Parkinson's disease: referral, consultation, and professional expertise." <u>Movement Disorders</u> **24**(2): 282-6.

Nowotny, M., A. Dachenhausen, et al. (2004). "Empowerment, quality of life and participation in neurological rehabilitation. Empirical study with stroke patients and their relatives." <u>Wiener Medizinische Wochenschrift,</u> **154**(23): 577-583.

Oppenheim, A. N. (1992). <u>Questionniare Design, Interviewing and Attitude Measurement</u>. London, Pinter Publishers.

Owen, A., M. James, et al. (1992). "Fronto-striatal cognitive deficits at different stages of Parkinson's disease." <u>Brain</u> **115**(6): 1727-51.

Oxtoby, M. (1982). Parkinson's Disease Patients and their Social Needs. London, Parkinson's Disease Society.

Pantelatos, A. and F. Fornadi (1993). "Clinical features and medical treatment of Parkinson's disease in patient groups selected in accordance with age at onset." <u>Advances in Neurology</u> **60**: 690-97.

Patton, M.Q. (1999) "Enhancing the Quality and Credibility of Qualitative Analysis". <u>Health Services Research</u> 34:5

PDS (1994). Meeting a Need? London, Parkinson's Disease Society.

PDS (1998). Carers Concerns. London, The Parkinson. **January 1998:** 13.

PDS (1998). Physical therapies. Part One: if you don't use it you lose it - physiotherapy. <u>The Parkinson</u>**:** 4-5.

PDS (1998). Physical therapies. Part Three: practical solutions to daily problems - occupational therapy. <u>The Parkinson</u>**:** 4-5.

PDS (1998). Physical therapies. Part Two: expressing yourself - speech and language therapy. <u>The Parkinson</u>**:** 4-5.

PDS (2001). Younger Parkinson's Survey. London, Parkinson's Disease Society.

PDS (2002). Quality of life in young people with Parkinson's.

PDS (2008). Life with Parkinson's today - room for improvement. London.

Pell, M. D., H. S. Cheang, et al. (2006). "The impact of Parkinson's disease on vocal-prosodic communication from the perspective of listeners." <u>Brain and Language</u> **97**(2): 123-134.

Perbohner, A. (1999). "Improving health: patient education resources on the internet." Healthcare on the internet **3**(3): 29-39.

Percival, R. and P. Hobson (1999). Parkinson's Disease: Studies in Psychological and Social Care. London, The British Psychological Society.

Peto, V., R. Fitzpatrick, et al. (1997). "Self-Reported Health status and Access to Health Services in a Community Sample with Parkinson's Disease." Disability and Rehabilitation **19**(3): 97-103.

Piovezan, M. R., H. A. Teive, et al. (2008). "Cognitive function assessment in idiopathic Parkinson's disease." Arq Neuropsiquiatr **66**(1): 142-3.

Pluck, G. and R. Brown (2002). "Apathy in Parkinson's disease." Journal of Neurology, Neurosurgery and Psychiatry **73**(6): 636-42.

Priestley (1998). Researching society and culture. C. Seale. London, Sage.

QSRInternational (1994). QSR NUD*IST. Melbourne, Qualitative Solutions & Research Pty Ltd.

Quinn, N., P. Critchley, et al. (1987). "Young Onset Parkinson's disease." Movement Disorders **2**: 73-91.

Rajput, A. and A. H. Rajput (2006). "Parkinson's disease management strategies." Expert Review of Neurotherapeutics **6**(1): 91-9.

Reason, P. and J. Rowan, Eds. (1981). Human Enquiry: A Sourcebook of New Paradigm Research. Chichester, John Wiley & Sons Ltd.

Reed, J. and S. Procter (1995). Practitioner Research in Health Care. London, Chapman Hall.

Reese, S. (1999). "Issues in caring for the patient with young-onset Parkinson's disease." Home Health Care Consultant **6**(4): 26-29.

Reeves, P. M. (2000). "Coping in Cyberspace: The Impact of Internet Use on the Ability of HIV-Positive Individuals to Deal with Their Illness." Journal of Health Communication **5**(supplement): 47-59.

Richard, I. H., A. W. Justus, et al. (2001). "Relationship between mood and motor fluctuations in Parkinson's Disease." J Neuropsychiatry Clin Neuroscience **13**: 35-41.

Rimmer, J., B. Riley, et al. (2005). "Accessibility of health clubs for people with mobility disabilities and visual impairments." American Journal of Public Health **95**(11): 2022-8.

Ring, H. (1993). "Psychological and social problems of Parkinson's disease." British Journal of Hospital Medicine **49**(2): 111-16.

Ritchie, J. and J. Lewis (2003). Qualitive Research Practice: A Guide for Social Science. London, Sage.

Robertson, D. (2008). "Rehabilitation in Parkinson's Disease." Journal Geriatric Medicine **10**(2): 51-57.

Robson, C. (2002). Real World Research. Oxford, Blackwell Publishing.

Roulstone, A., L. Gradwell, et al. (2003). Thriving and surviving at work: disabled people's employment strategies. Bristol, Policy Press.

Royle, J., Steel, R., Hanley, B., Bradburn, J. (2001) Getting Involved in Research: a Guide for Consumers. Winchester: Consumers in NHS Research Support Unit.

Rubenstein, L.M.,DeLeo, A., and Chrischilles, E.A. (2001). "Economic and Health-Related Quality of Life Considerations of New Therapies in Parkinson's Disease." Pharmacoeconomics **19** (7) 729 - 752

Rumrill, P., R. T. Roessler, et al. (2004a). "Vocational Rehabilitation predictors of quality of life among people with Multiple Sclerosis." Journal of Vocational Rehabilitation **20**: 155-163.

Rumrill, P., R. Roessler, et al. (2004b). "Workplace Barriers and Job Satisfaction Among Employed People With Multiple Scerosis: An Empirical Rationale For Early Intervention." Journal of Vocational Rehabilitation **20**(177-83).

Schrag, A. and P. Banks (2006). "Time of loss of employment in Parkinson's disease." Movement Disorders **21**(11): 1839-1843.

Schrag, A., Y. Ben-Shlomo, et al. (1998). "Young-onset Parkinson's disease revisited - clinical features, natural history and mortality." Movement Disorders **13**(6): 885-94.

Schrag, A., A. Hovris, et al. (2003). "Young- versus older-onset Parkinson's disease: Impact of disease and psychosocial consequences." Movement Disorders **18**(11): 1250-1256.

Schrag, A., M. Jahanshahi, et al. (2001). "What contributes to depression in Parkinson's disease?" Psychological Medicine **31**: 65 - 73.

Schreurs, K., D. D. Ridder, et al. (2000). "A One Year Study of Coping, Social Support and Quality of Life in Parkinson's Disease." Psychology and Health **15**: 109 - 121.

Scwandt, T. A. (1997). Qualitative Inquiry: A Dictionary of Terms. London, Sage Publications.

Shapira, A. (2006). "Etiology of Parkinson's disease." American Academy of Neurology **66**: S10-S23.

Shiba, M., J. Bower, et al. (2000). "Anxiety disorders and depressive disorders preceding Parkinson's disease: a case-control study." Movement Disorders **15**(4): 669-677.

Shulman, L., R. Taback, et al. (2002). "Non-recognition of depression and other non-motor symptoms in Parkinson's disease." Parkinsonism & Related Disorders **8**(3): 193-97.

Social Services Inspectorate. (2001). "Making it work: Inspection of Welfare to Work for Disabled People", Department of Health.

Starkstein, S., T. Preziosi, et al. (1989). "Depression and Cognitive Impairment in Parkinson's Disease." Brain **112**(5): 1141 - 1153.

Steward, B. (1996). "Unemployment and health 1: the impact of unemployment on clients in therapy and rehabilitation." British Journal of Therapy and Rehabilitation **3**(7): 360 - 363.

Strawbridge, W. J., S. Deleger, et al. (2002). "Physical Activity Reduces the Risk of Subsequent Depression for Older Adults." American Journal of Epidemiology **156**(4): 328-334.

Sullivan, K. L., C. L. Ward, et al. (2007). "Prevalence and treatment of non-motor symptoms in Parkinson's disease." Parkinsonism & Related Disorders **13**(8): 545.

Sweetland, J., A. Riazi, et al. (2007). "Vocational rehabilitation services for people with Multiple Sclerosis: what patients want from clinicians and employers." Multiple Sclerosis **13**: 1183-1189.

Tamaru, F. (1997). "Disturbances in higher function in Parkinson's disease." European Journal of Neurology **38**(2): 33-36.

Taylor, J. P., E. N. Rowan, et al. (2008). "Poor attentional function predicts cognitive decline in patients with non-demented Parkinson's disease independent of motor phenotype." Journal of Neurology, Neurosurgery and Psychiatry **79**(12): 1318-23.

Thomas, C. (1999a). Female Forms: Experiencing and understanding disability. Buckingham, Open University Press.

Thomas, S. (1999b). "Parkinson's disease." Elderly Care **11**(3): 33.

Thompson, A. and E. Playford (2001). "Rehabilitation for people with Parkinson's disease (letter)." The Lancet **357**: 410-11.

Thurgood, J. and A. O. Frank (2007). "Work is beneficial for Health and Wellbeing: Can Occupational Therapists Now Return to their Roots?" British Journal of Occupational Therapy **70**(2): 49.

Tickle-Degnen, L. and K. D. Lyons (2004). "Practitioners' impressions of patients with Parkinson's disease: The social ecology of the expressive mask." Social Science & Medicine **58**(3): 603-614.

Timmons, S. (2001). "The use of the internet by patients: not a threat to nursing, but an opportunity?" Nurse Education Today **21**(2): 104 - 109.

Townsend, E. (2002). Enabling Occupation:an occupational therapy perpective, Canadian Association of Occupational Therapists.

Townsend, G. (2008). "Supporting People with Multiple Sclerosis in Employment: a United Kingdom Survey of Current Practice and Experience." British Journal of Occupational Therapy **71**(3): 103-111.

Tse, D.W. and Spalding S.J. (1998). "Review of motor control and motor learning: implications for occupational therapy with Parkinson's disease." Physical and Occupational Therapy in Geriatrics **15** (3): 19 - 38

Turnbull, A. (2001). On-line support, quality of life and disease management in Parkinson's disease, Staffordshire University.

Unger, D., P. D. Rumrill, et al. (2004). "A comparative analysis of employment discrimination complaints filed by people with Multiple Sclerosis and individuals with other disabilities." Journal of Vocational Rehabilitation **20**(165-170).

Van Gool, C. H., G. I. J. M. Kempen, H. Bosma, M.P.J. van Boxtel, J. Jolles and J.T.M. van Eijk (2007). "Associations Between Lifestyle and Depressed Mood: Longitudinal Results From the Maastricht Aging Study." American Journal of Public Health **97**(5): 887-894.

Varekamp, I., Verbeek, J. H., van Dijk, F.J., et al. (2006). "How can we help employees with chronic illness to stay at work?" Int arch occup environ health **80**: 87-97.

Varekamp, I., de Vries, G., Heutink, A., and van Dijk, F.J. (2008) "Empowering employees with chronic diseases; development of an intervention aimed at job retention and design of a randomised controlled trial." Health Services Research **8**(3) 1472 - 6963

Varekamp, I., Heutink, A., Landman, S., Koning, C.E.M., de Vries, G., and van Dijk, F.J. (2009) "Facilitating Empowerment in Employees with Chronic Disease: Qualitative Analysis of the Process of Change" Journal of Occupational Rehabilitation **19** (4) 398 - 408

Vaughn, S., J. S. Schumm, et al. (1996). Focus Group Interviews in Education and Psychology. Thousand Oaks, SAGE.

Velde, P. (1997). Quality of life through personally meaningful activity. Quality of Life for People with Disabilities. R. I. Brown. Cheltenham, Stanlry Thornes (Publishers) Ltd. **2**.

Waddell, G. and A. Burton (2006). Is work good for your health and wellbeing? London, TSO.

Wallhagen, M. I. and M. Brod (1997). "Perceived Control and Well-Being in Parkinson's Disease." <u>Western Journal of Nursing Research</u> **191**(1): 11 - 31.

Wilcock, A. A. (2002). "A Theory of the Human Need for Occupation." <u>Journal of Occupational Science</u> **9**(Special Issue).

Wilson, R. S., D. W. Gilley, et al. (1992). "Ideational fluency in Parkinson's disease." <u>Brain and Cognition</u> **20**(2): 236-44.

Witjas, T., E. Kaphan, et al. (2002). "Nonmotor fluctuations in Parkinson's Disease: Frequesnt and disabling." <u>Neurology</u> **59**(3): 408 - 413.

Wright, J. (1999). "Nonpharmacologic management strategies." <u>Medical Clinics of North America</u> **83**(2): 499-508.

Yarrow, S. (1999). Survey of Members of the Parkinson's Disease Society. London, Parkinson's Disease Society.

Yildiz, H., A. Icagasioglu, et al. (2006). "Quality of life in multiple sclerosis." <u>Goztepe Tip Dergisi</u> **21**(1): 36-39.

Zesiewicz, T.A., Patel-Larson, A., Hauser, R.A. and Sullivan, K.L. (2007) "Social Security Disability Insurance (SSDI) in Parkinson's disease." <u>Disability and Rehabilitation</u> **29** (24): 1934 -6

Ytterberg, C., S. Johansson, et al. (2008). "Perceived needs and satisfaction with care in people with multiple sclerosis: A two-year prospective study." <u>BMC Neurology</u> **8**(36).

Zgaljardic, D. J., J. C. Borod, et al. (2003). "A review of the cognitive and behavioral sequelae of Parkinson's disease: relationship to frontostriatal circuitry." <u>Cognitive Behavioural Neurology</u> **16**(4): 193-210.

Zunzunegui, M., B. E. Alvarado, et al. (2003). "Social Networks, Social Integration, and Social Engagement Determine Cognitive Decline in Community-Dwelling Spanish Older Adults." <u>The Journals of Gerontology Series B: Psychological Sciences and Social Sciences</u> 58

Appendix A - Letter to Parkinson's Disease Nurse Specialists requesting assistance with recruitment

On headed paper

Date

Dear Parkinson's Disease Nurse Specialist,

RE: An investigation into the use of an internet-based self-management programme to promote the maintenance of employment and leisure roles in younger people with Parkinson's.

The above project has been funded by the Parkinson's Disease Society (grant reference 8035, contact [*PDS Research Officer*] on [*tel.no.*]) and has been given approval by the Northern and Yorkshire Multi-Centre Research Ethics Committee (reference MREC/3/3/47 contact [*MREC Officer*] on [*tel.no.*]).

I would like to ask for your help in distributing the enclosed questionnaire packs to enable data collection for this project. The packs should be distributed to 2 people on your caseload who meet the following criteria:

- Have a diagnosis of Parkinson's Disease

- Have been diagnosed for at least 12 months

- Who were diagnosed under the age of 45

- Who are currently under the age of 65

- Who are willing to participate in the study

I would be grateful if you could please distribute them within two weeks of receipt of this letter.

I have enclosed an abstract to provide you with a description of the project. If you have any queries, please do not hesitate to contact me by phone on [*tel.no.*] or by e-mail at [*email address of researcher*]

Your help with this project is extremely valuable, and I thank you in advance for your contribution.

Yours Sincerely,

Angela Birleson

Version 1.3

Appendix B Abstract of Study for PDNS (Version 1.2)

An investigation into the use of an internet-based self-management programme to promote the maintenance of employment and leisure roles in younger people with Parkinson's.

 Although Parkinson's is often considered a disease of old age, 1 in 7 people with this condition will have been diagnosed when they were under the age of 50. People in this age range are often in paid employment or are making plans for an active retirement. They usually have many family responsibilities, caring for children, or grandchildren or elderly parents. Social and leisure networks are well established and will include a wide range of activities. However, once a diagnosis of Parkinson's is received, this picture changes. Studies have identified that many people with Parkinson's experience difficulty in maintaining their social activities and their employment with the repercussions of early retirement are seen as being more than financial and can require considerable emotional and psychological adjustments.

The abandonment of employment and leisure activities is not always a direct result of physical impairment other factors are involved. In social situations, some people with Parkinson's report that they feel inclined to retreat due to their embarrassment in situations in which they are required to walk, talk or eat which can then result in social isolation and depression. The effect of this withdrawal from social situations should not be underestimated as it impacts not only on the individual, but on their whole family and social circle. Despite this, people with Parkinson's rarely receive intervention from health or social services to enable them to maintain their employment and leisure roles. The type of intervention that people required to enable them to maintain their roles despite the physical, psychological, social and environmental difficulties experienced could be delivered in the form of a self-management programme. The education of people with long term conditions to empower them to make informed choices regarding the management of their condition i.e. developing 'Expert Patients' has recently been raised as an issue by the DoH. However, self-management programmes for people with Parkinson's where available are under utilised by the younger age group. A variety of reasons are responsible, such as timing of the programme i.e. during 'normal' working hours, a reticence to mix with older people, or simply that the content of the programmes are not specifically geared to the needs of younger people.

In this research project, a nationwide survey will be undertaken with younger people who have Parkinson's. They will be asked to complete a questionnaire about their work and leisure activities and also their experience of self-management programmes. Two focus groups will be undertaken to supplement this information and discuss issues further. Using the responses from the survey and focus groups, a self-management programme for younger people with Parkinson's will be developed. The results of an examination of the roles and provision of statutory and non-statutory services will contribute to the programme.

The programme will designed to be delivered electronically via a web-site, as using electronic communication would allow the programme to be accessed at a convenient time and in a suitable location for younger people. The internet is currently being hailed as an effective method for delivering health education including self-management programmes, and increasing numbers of people have access to the internet and are comfortable with its use. The programme will be reviewed by a group of people with Parkinson's and changes made if appropriate before the programme goes on-line. Links to the Parkinson's Disease Society site and other appropriate sites will be made.

Appendix C Consent Form

Title of Project: An investigation into the use of an internet-based self-management programme to promote the maintenance of employment and leisure roles in younger people with Parkinson's

Name of Researcher: Angela Birleson

Please initial box

I confirm that I have read and understand the information sheet
(June 2003 Version 1.2) for the above study.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I agree to take part in the above study.

_____   _____ _____

Name of Participant   Date   Signature

_____   _____ _____

Name of Researcher   Date   Signature

Please retain one copy and send the other back with the questionnaire.

June 2003

Appendix D Information Sheet for Participants

The Effect of Parkinson's Disease on Employment & Leisure Roles

My name is Angela Birleson, I am an occupational therapist with experience of working with people who have Parkinson's and also carrying out research into living with Parkinson's. The Parkinson's Disease Society have funded this research and the project will hopefully be of benefit to all younger people like yourself with this condition. I would greatly appreciate your participation in this project, however before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

- *How have I been chosen?*

These packs were sent to all the Parkinson's Disease Nurses in the UK. Each nurse was asked to distribute two packs to people with Parkinson's aged under 65.

- *What do I have to do to take part?*

Participation in this study will require you to complete the attached questionnaire, which should take around 25 minutes. It is up to you to decide whether or not to take part, your participation is entirely voluntary. Please discuss this with others if you wish and a contact number is given at the end of this sheet if you wish to ask any questions. If you do decide to take part, you will need to complete both consent forms, keep a copy for yourself and return the other copy with the completed questionnaire in the envelope provided within 3 weeks.

- *What is the purpose of the study?*

Although Parkinson's Disease is often considered a disease of old age, 1 in 7 people with it will have been diagnosed under the age of 50. People of this age are often in paid employment, making plans for an active retirement or have many family

responsibilities. Social and leisure networks are well established and include a wide range of activities. However, once a diagnosis of Parkinson's is received, this picture changes. Studies have identified that many people with Parkinson's experience difficulty in maintaining their social activities and employment. The effect of the loss of employment and withdrawal from social situations can be considerable, yet people with Parkinson's rarely receive help to assist them to maintain these activities.

A self-management programme could provide help for younger people with Parkinson's to maintain their employment and leisure activities. Self-management programmes are usually a series of presentations on subjects that enable you to manage your condition more effectively. However, often, self-management programmes are under utilised by younger people due to the timing of the programme, not wanting to mix with older people, or the content of the programmes not being geared to the needs of younger people.

This study aims to create a self-management programme to promote the maintenance of employment and leisure roles in younger people with Parkinson's and will be placed on a web-site, so that it can be accessed at a convenient time and place. The programme will reflect the experiences of younger people with Parkinson's drawn from a postal questionnaire and focus groups. Once completed, the web-based programme will be evaluated by a group of younger people with Parkinson's.

- ***Will my taking part in this study be kept confidential?***

The information collected from the questionnaire will be strictly confidential. At no point will your name or identifying characteristics be used in the report or any subsequent publications.

 Your GP and consultant have not been informed about your involvement in the study, however if you wish, you can tell them yourself, or send them a copy of this information sheet.

- ***What will happen to the results of the research study?***

The results of the study will be sent to the Parkinson's Disease Society. A copy of these results will be available from the Parkinson's Disease Society following completion of the study in Spring 2005. You will also be able to view the completed web-site, the

address is yet unknown but there will be a link from the Parkinson's Disease Society Home Page. The results will also be used in the researcher's PhD submission. The results will then be published in appropriate journals to share the findings. In both the report to the Parkinson's Disease Society and in any journal articles you will not be identified.

- *Who is organising and funding the research?*

This project is being funded by the Parkinson's Disease Society UK. Supervision of the study is being carried out by the University of Northumbria.

- *Who has reviewed the study?*

This study has been reviewed and approved by:

The Multi-Centre Research Ethics Committee (MREC).

Parkinson's Disease Society UK.

Northumbria University

- *Contact for Further Information*

If you require any further information, please contact:

By telephone:	By e-mail:	By post:
Angela Birleson [*tel.no*]	Angela.Birleson@[*email*]	Angela Birleson [*address*]

Thank you once again for taking the time to read this.

June 2003 Version

Appendix E Questionnaire (hard copy)

The Effect of Parkinson's Disease on Employment & Leisure Roles

Thank you for agreeing to take part in this survey. This questionnaire should only take around 25 minutes of your time to complete. Please respond to each question by either inserting an answer or by circling one of the options suggested. Please use a black pen.

About You …

In this section I want to find out about you by asking you to answer some simple questions

---

A1	How old are you	λ	
A2	Are you male or female?	⊇ male	⊄ female
A3	How many years is it since you were diagnosed with Parkinson's?	λ	
A4	Do you currently live alone?	⊇ yes	⊄ no
A5	If you live with others, what is their relationship to you (e.g. wife, son, partner)?	λ	
A6	Can you please insert the first two letters of your postcode	λ	

Employment …

In this section I want to find out about your employment history and if Parkinson's has had any impact on it. For the purpose of this questionnaire, employment can be paid or unpaid. Unpaid employment may include voluntary work or childminding. If you have never been in employment, please ignore this section and go to the next one.

B1	Can you describe the last post you held or are currently in? (e.g. 'part-time' and 'paid')	⊇ Full time ⊂ Paid	⊄ Part-time ⊆ Unpaid
B2	What is the title or nature of the post?	λ	
B3	Are you currently employed?	⊇ yes (go to **B13**)	⊄ no

B4	Did you leave work because of your Parkinson's?	⊇ yes ⊄ no (go to **B6**)
B5	If no, can you describe your reasons for leaving?	λ (go to **B16**)
B6	On what basis did you leave employment (e.g. 'early retirement', 'redundancy' etc.)?	λ
B7	How old were you when you left employment?	λ
B8	How long following your diagnosis did you give up work?	λ

B9	If you hadn't had Parkinson's, what age did you imagine you would retire?	λ
B10	What were your reasons for giving up work? (e.g. 'fatigue', 'physically unable to cope with the job', 'lack of understanding from colleagues' etc.)	λ
B11	Would you like to have remained employed?	⊇ yes ⊄ no
B12	What did you do to fill in your time in after you left work?	λ
B13	How long after your diagnosis did you inform your employer that you had Parkinson's?	λ
B14	Did you or have you adapted your working arrangements to accommodate Parkinson's?	⊇ yes ⊄ no (go to **B16**)
B15	What adaptations did you make? (e.g. 'reduced hours', 'using specialised equipment', 'changing your work role' etc.)	λ

B16	Do you think there are any benefits of remaining in employment?	⊇ yes	⊄ no (go to **B18**)
B17	Can you please describe the benefits of remaining in employment?	λ	
B18	Did you seek assistance to enable you to remain in employment (either your existing job or another)?	⊇ yes	⊄ no
B19	Where did you look for assistance? (e.g. 'asked the GP', 'rang the job centre', 'asked my consultant' etc.)		
B20	Did you/have you received any assistance in helping you to remain in employment?	⊇ yes	⊄ no (go to **B22**)
B21	I'd like you to please describe the assistance you received. Who provided the assistance?	λ	
	How did you find out about it?	λ	
	What did they do for you?	λ	
	How successful was it?	λ	
B22	Would you like to have received assistance to enable you to remain in work?	⊇ yes	⊄ no

Leisure Activities …

In this section I want find out about the things you do or used to do with your leisure time.

C1	Can you describe below your leisure activities **prior to having Parkinson's** (e.g. crafts, sport, social activities), how frequently you engaged in them, and how long you spent doing them per session? (If you had more than 6 activities can you please prioritise them and record only the 6 most important activities, or the ones that meant the most to you).

Activity	Frequency	Length of time per session	Effect Parkinson's has had on this activity
e.g. Gardening	**e.g.** 4 times per week	**e.g.** 2 hours	**e.g.** reduced amount of time spent on activity

C2	Can you summarise the effect that Parkinson's has had overall on your leisure activities?	λ
C3	If you gave up any of your leisure activities, what were the reasons? (e.g. 'fatigue', 'embarrassment', 'physical difficulties' etc.)	λ
C4	Can you list the leisure activities you have given up since having Parkinson's?	λ

C5	Can you describe below, your **current** leisure activities (e.g. crafts, sport, social activities), how frequently you engage in them and how long you spend doing them per session? (If you have more than 6 activities can you please prioritise them and record only the 6 most important activities, or the ones that mean the most to you).

Activity	Frequency	Length of time per session	Is this a new activity or one you carried out prior to Parkinson's?
e.g. swimming	**e.g**. 3 times per week	**e.g**. 1 hour	**e.g**. new activity

C6	Can you list the new activities you have taken up since having Parkinson's?	λ	
C7	Did you seek assistance to enable you to maintain your leisure activities?	λ	⊄ no (go to **C9**)
C8	Where did you look for assistance? (e.g. 'asked the GP', 'rang the sports centre', 'asked my consultant' etc.)	λ	
C9	Did you receive any help to maintain your leisure roles? (e.g. 'support from services', 'information at leisure centre')	⊇ yes	⊄ no (go to **C11**)
C10	I'd like you to please describe the assistance you received. Who provided the assistance?	λ	
	How did you find out about it?	λ	
	What did they do for you?	λ	
	How successful was it?	λ	
C11	Would you like to have received assistance to enable you to maintain your leisure activities?	λ	⊄ no
C12	Do you think there are any benefits in maintaining your leisure activities?	⊇ yes	⊄ no (go to **D1**)
C13	If yes, can you please describe them?	λ	

Self-management …

In this section I want to find out about any self-management programmes you may have experienced. A self-management programme is usually organised by health professionals (possibly a Parkinson's Disease Nurse) and aims to inform you about how you can best manage your Parkinson's. It usually consists of a series of sessions containing information about different aspects of Parkinson's

D1	Have you ever been offered the opportunity to attend a self-management programme?	⊇ yes	⊄ no (go to **D10**)
D2	Were you offered attendance and declined?	⊇ yes	⊄ no (go to **D4**)
D3	Why did you decline? (e.g. 'wrong time', 'location', 'age group')	λ	
D4	I'd like you to please describe the programme you attended. How many sessions did the programme have?	λ	
	How long were the sessions?	λ	
	Where were they held?	λ	
	What topics did the programme cover?	λ	
	Which professionals were involved in the programme?	λ	
D5	Did any of the sessions cover maintaining employment and leisure roles?	⊇ yes	⊄ no
D6	Did you feel the programme benefited you in any way?	⊇ yes	⊄ no (got to **D8**)
D7	How? (e.g. 'as a social outlet', 'contact with professionals', 'increased knowledge regarding the progression of Parkinson's' etc)	λ	

D8	Was there a particular session or topic that you found useful? Please describe.	λ	
D9	Was there anything missing from the programme that you felt should have been included? Please describe.	λ	
D10	Would you like to attend a self-management programme?	⊇ yes	⊄ no (go to **D12**)
D11	In what way do you think you will benefit from a self-management programme?	λ (go to **D13**)	
D12	What are your reasons for not wanting to attend a self-management programme?	λ	
D13	If you require information regarding your Parkinson's who do you go to for what type of information? (e.g. 'Parkinson's Nurse for advice about medication', 'Disability Advice Centre for information about benefits')	λ	

Use of the Internet …

In this section I want to find out about your use of the internet, and if you use it to search for information about Parkinson's.

E1	Do you have ready access to the Internet?	⊇ yes	⊄ no
E2	Where could you access the Internet? (e.g. 'at home', 'library', 'friends or family home' etc.)	λ	
E3	Have you ever used it to access health care information?	⊇ yes	⊄ no
E4	Have you used it to access information about Parkinson's?	⊇ yes	⊄ no (go to **E6**)

E5	What type of information about Parkinson's have you managed to access? (e.g. 'about drugs', 'surgery', 'exercise' etc.)	λ	
E6	Have you ever tried to access information about maintaining your employment and leisure activities?	⊇ yes	⊄ no (go to **E9**)
E7	Did you manage to find any?	⊇ yes	⊄ no (go to **E9**)

E8	How satisfied were you with the level of information on offer with regard to employment ?	⊇ Highly ⊂ Not at all	⊄ Moderately
	… and with regard to leisure?	⊇ Highly ⊂ Not at all	⊄ Moderately
E9	Would you access information about employment and leisure activities if it were easily available on the internet?	⊇ yes (go to **E11**)	⊄ no
E10	As you have not tried to access information about employment and leisure, could you describe your reasons for not doing so?	λ	
E11	What sort of information regarding employment and leisure activities would you like to see on the internet?	λ	
E12	Have you ever used an Internet support group?	⊇ yes	⊄ no (go to **E15**)
E13	Can you please describe it? (e.g. 'related to Parkinson's')	λ	
E14	In what way have you benefited from using the group?	λ	

You have now finished the questionnaire.

Please return this questionnaire in the envelope provided, and don't forget to include your signed consent form.

Your time and effort in taking part is much appreciated.

If this questionnaire has raised any issues for you that you have found distressing or would like to talk further about, the Parkinson's Disease Society have a help-line that is staffed by qualified nurses.

The number is Freephone 0808 8000303

Appendix F   Information Sheet for participants (electronic version)

The Effect of Parkinson's Disease
on **Employment & Leisure**
Activities

My name is Angela Birleson, I am an occupational therapist with experience of working with people who have Parkinson's and also carrying out research into living with Parkinson's. The Parkinson's Disease Society have funded this research and the project will hopefully be of benefit to all younger people like yourself with this condition. I would greatly appreciate your participation in this project, however before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Contact me if there is anything that is not clear or if you would like more information.

What do I have to do to take part?

Participation in this study will require you to complete a simple questionnaire, which should take around 25 minutes. Your participation is entirely voluntary and you can e-mail me if you have any questions.

I am looking for people who fulfil all the following criteria to take part:

- Are under 65 years old
- Were diagnosed with Parkinson's when they were under 45
- Have been diagnosed with Parkinson's for at least 1 year

What is the purpose of the study?

Although Parkinson's Disease is often considered a disease of old age, 1 in 7 people with it will have been diagnosed under the age of 50. People like yourself in this age range are often in paid employment, perhaps making plans for an active retirement or have many family responsibilities. Your social and leisure networks are well established and include a wide range of activities (when you have time to fit them in!). However, sometimes when a diagnosis of Parkinson's is received, this picture changes. Research carried out has identified that many people with Parkinson's experience difficulty in maintaining their social activities and employment. The effect of the loss of employment and withdrawal from social situations can be considerable, yet people with Parkinson's rarely receive help to assist them to maintain these activities.

The aim of this research is to compile a programme that could provide help for younger people with Parkinson's to maintain their employment and leisure activities. The first step in this process is to find out about the experiences of younger people with Parkinson's in relation to their employment and leisure activities. This is

being done in the form of a nationwide questionnaire which has been sent out to some people by post, in addition to being available electronically on this site. In order to gain an accurate picture of what is currently happening, as many younger people with Parkinson's are needed to fill in and return the questionnaire. This information will then help to guide the development of a programme to promote the maintenance of employment and leisure roles in younger people with Parkinson's.

Confidentiality/ data protection

The information collected from the questionnaire will be strictly confidential. At no point will your name or identifying characteristics be used in the report or any subsequent publications.

What will happen to the results of the study?

The results of the study will be sent to the Parkinson's Disease Society. A copy of these results will be available from the Parkinson's Disease Society following completion of the study in Spring 2005. You will also be able to view the completed web-site, the address is yet unknown but there will be a link from the Parkinson's Disease Society Young Person's Site. The results will also be used in the researcher's PhD submission. The results will then be published in appropriate journals to share the findings. In both the report to the Parkinson's Disease Society and in any journal articles you will not be identified.

Who is organising and funding the research?

This project is being funded by the Parkinson's Disease Society UK. Supervision of the study is being carried out by the University of Northumbria.

Who has reviewed the study?

This study has been reviewed and approved by:

✓ The Multi-Centre Research Ethics Committee (MREC).

✓ Parkinson's Disease Society UK.

✓ Northumbria University

Once again, I am very grateful for all your help.

Yours Sincerely,

Angela Birleson.

Contact for Further Information

If you require any further information, please contact:

Main Contact	Telephone Number	Address
Angela Birleson		

Appendix G Questionnaire (electronic version)

The Effect of Parkinson's

Disease

on Employment & Leisure

Activities

Thank you for agreeing to take part in this survey. This questionnaire should only take around 25 minutes of your time to complete. Please respond to each question by either inserting an answer or by clicking one of the options suggested. Thank you.

SECTION A: About You …

In this section I want to find out about you by asking you to answer some simple questions

A1	How old are you	
A2	Are you male or female?	Male ○ Female ○
A3	How old were you when you were diagnosed with Parkinson's?	
A4	Do you currently live alone?	Yes ○ No ○
A5	If you live with others, what is their relationship to you (e.g. wife, son, partner)?	
A6	Can you please insert the first two letters of your postcode	

SECTION B: Employment

In this section I want to find out about your employment history and if Parkinson's has had any impact on it. For the purpose of this questionnaire, employment can be paid or unpaid. Unpaid employment may include voluntary work or childminding. If you have never been in employment, please ignore this

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section and go to the next one.

B1	Can you describe the last post you held or are currently in? (e.g. 'part-time' and 'paid')	Full time ○ Part-time ○ Paid ○ Unpaid ○
B2	What is the title or nature of the post?	
B3	Are you currently employed?	Yes ○ No ○ **Note:** If 'yes' please skip to Question B13
B4	Did you leave work because of your Parkinson's?	Yes ○ No ○ **Note:** If 'yes' please skip to Question B6
B5	If no, can you describe your reasons for leaving?	**Note:** Now please skip to Question B16
B6	On what basis did you leave employment (e.g. 'early retirement', 'redundancy' etc.)?	
B7	How old were you when you left employment?	
B8	How long following your diagnosis did you give up work?	
B9	If you hadn't had Parkinson's, what age did you imagine you would retire?	
B10	What were your reasons for giving up work? (e.g. 'fatigue', 'physically unable to cope with the job', 'lack of understanding from colleagues' etc.)	
B11	Would you like to have remained employed?	Yes ○ No ○
B12	What did you do to fill in your time after you left work?	
B13	How long after your diagnosis did you inform your employer that you had Parkinson's?	
B14	Did you or have you adapted your working arrangements to accommodate Parkinson's?	Yes ○ No ○ **Note:** If 'no' please skip to Question B16
B15	What adaptations did you make? (e.g. 'reduced hours', 'using specialised equipment', 'changing work role' etc.)	

B16	Do you think there are any benefits of remaining in employment?	Yes ○ No ○ **Note:** If 'no' please skip to Question B18
B17	Can you please describe the benefits of remaining in employment?	[ ]
B18	Did you seek assistance to enable you to remain in employment (either your existing job or another)?	Yes ○ No ○ **Note:** If 'no' please skip to Question B20
B19	Where did you look for assistance? (e.g. 'asked the GP', 'rang the job centre', 'asked my consultant' etc.)	[ ]
B20	Did you/have you received any assistance in helping you to remain in employment?	Yes ○ No ○ **Note:** If 'no' please skip to Question B22
B21	I'd like you to please describe the assistance you received.	
	Who provided the assistance?	[ ]
	How did you find out about it?	[ ]
	What did they do for you?	[ ]
	How successful was it?	[ ]
B22	Would you like to have received assistance to enable you to remain in work?	Yes ○ No ○

SECTION C: Leisure

In this section I want find out about the things you do or used to do with your leisure time.

C1	Can you describe below your leisure activities prior to having Parkinson's (e.g. crafts, sport, social activities), how frequently you engaged in them, and how long you spent doing them per session? (If you had more than 6 activities can you please prioritise them and record only the 6 most important activities, or the ones that meant the most to you).

	Activity	Frequency	Length of time per session	Effect Parkinson's has had on this activity
eg.	Gardening	4 times a week	2 hours	Reduced amount of time spent on activity and stopped doing heavy work

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	Activity	Frequency	Length of time per session	Is this a new activity or one you carried out prior to Parkinson's?
1.				
2.				
3.				
4.				
5.				
6.				

C2 Can you summarise the effect that Parkinson's has had overall on your leisure activities?

C3 If you gave up any of your leisure activities, what were the reasons? (e.g. 'fatigue', 'embarrassment', 'physical difficulties' etc.)

C4 Can you list any leisure activities you have given up since having Parkinson's?

C5 Can you describe below, your current leisure activities (e.g. crafts, sport, social activities), how frequently you engage in them and how long you spend doing them per session? (If you have more than 6 activities can you please prioritise them and record only the 6 most important activities, or the ones that mean the most to you).

	Activity	Frequency	Length of time per session	Is this a new activity or one you carried out prior to Parkinson's?
eg.	Swimming	3 times a week	1 hours	New acitivity
1.				
2.				
3.				
4.				
5.				
6.				

C6 Can you list any new activities you have taken up since having

	Parkinson's?	
C7	Did you seek assistance to enable you to maintain your leisure activities?	Yes ◯ No ◯ **Note:** If 'no' please skip to Question C9
C8	Where did you look for assistance? (e.g. 'asked the GP', 'rang the sports centre', 'asked my consultant' etc.)	[ ]
C9	Did you receive any help to maintain your leisure roles? (e.g. 'support from services', 'information at leisure centre')	Yes ◯ No ◯ **Note:** If 'no' please skip to Question C11
C10	I'd like you to please describe the assistance you received.	
	Who provided the assistance?	[ ]
	How did you find out about it?	[ ]
	What did they do for you?	[ ]
	How successful was it?	[ ]
C11	Would you like to have received assistance to enable you to maintain your leisure activities?	Yes ◯ No ◯
C12	Do you think there are any benefits in maintaining your leisure activities?	Yes ◯ No ◯ **Note:** If 'no' please skip to Question D1
C13	If yes, can you please describe them?	[ ]

SECTION D: Self Management

In this section I want to find out about any self-management programmes you may have experienced. A self-management programme is usually organised by health professionals (possibly a Parkinson's Disease Nurse) and aims to inform you about how you can best manage your Parkinson's. It usually consists of a series of sessions containing information about different aspects of your condition.

D1	Have you ever been offered the opportunity to attend a self-management programme?	Yes ◯ No ◯ **Note:** If 'no' please skip to Question D11
D2	Were you offered attendance and declined?	Yes ◯ No ◯ **Note:** If 'no' please skip to Question D4

D3	Why did you decline? (e.g. 'wrong time', 'location', 'age group')	_____ Now
		please skip to Question D11
D4	I'd like you to please describe the programme you attended.	
	How many sessions did the programme have?	_____
	How long were the sessions?	_____
	Where were they held?	_____
	What topics did the programme cover?	_____
	Which professionals were involved in the programme?	_____
D5	Did any of the sessions cover maintaining employment and leisure roles?	Yes ○ No ○ **Note:** If 'no' please skip to Question D7
D6	If yes, can you describe the content of the sessions covering employment and leisure	_____
D7	Did you feel the programme benefited you in any way?	Yes ○ No ○ **Note:** If 'no' please skip to Question D9
D8	How? (e.g. 'as a social outlet', 'contact with professionals', 'increased knowledge regarding the progression of Parkinson's' etc)	_____
D9	Was there a particular session or topic that you found useful? Please describe.	_____
D10	Was there anything missing from the programme that you felt should have been included? Please describe.	_____ Now
		please skip to Question D14
D11	Would you like to attend a self-management programme?	Yes ○ No ○ **Note:** If 'no' please skip to Question D13
D12	In what way do you think you will benefit from a self-management programme?	_____ Now
		please skip to Question D14
D13	What are your reasons for not wanting to attend a self-management programme?	_____

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D14	If you require information regarding your Parkinson's who do you go to for what type of information? (e.g. 'Parkinson's Nurse for advice about medication', 'Disability Advice Centre for information about benefits')	

SECTION D: Use of the internet

In this section I want to find out about your use of the internet, and if you use it to search for information about Parkinson's.

E1	Do you have ready access to the Internet?	Yes ○ No ○
E2	Where could you access the Internet? (e.g. 'at home', 'library', 'friends or family home' etc.)	
E3	Have you ever used it to access health care information?	Yes ○ No ○
E4	Have you used it to access information about Parkinson's?	Yes ○ No ○ **Note:** If 'no' please skip to Question E6
E5	What type of information about Parkinson's have you managed to access? (e.g. 'about drugs', 'surgery', 'exercise' etc.)	
E6	Have you ever tried to access information about maintaining your employment and leisure activities?	Yes ○ No ○ **Note:** If 'no' please skip to Question E9
E7	Did you manage to find any?	Yes ○ No ○ **Note:** If 'no' please skip to Question E9
E8	How satisfied were you with the level of information on offer:	
	with regard to employment ?	Highly ○ Moderately ○ Not at all ○
	with regard to leisure ?	Highly ○ Moderately ○ Not at all ○
E9	Would you access information about employment and leisure activities if it were easily available on the internet?	Yes ○ No ○ **Note:** If 'yes' please skip to Question E11
E10	As you have not tried to access information about employment and leisure, could you describe your reasons for not doing so?	

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E11	What sort of information regarding employment and leisure activities would you like to see on the internet?	
E12	Have you ever used an Internet support group?	Yes ○ No ○ **Note:** If 'yes' please skip to Question E15
E13	Can you please describe it? (e.g. 'related to Parkinson's')	
E14	In what way have you benefited from using the group?	

Name		Telephone	
Address		Email	
Town / County			
Postcode			

Thank you! **Please click the submit button to finish this questionnaire.**

Submit Answers

Appendix H Focus Group Schedule

- **Introduction**

- **Confidentiality and Consent**

- **Comfort and interruptions**

- **General Purpose Statement**

Parkinson's Disease often has a dramatic effect on the employment and leisure activities of younger people. However, younger people with Parkinson's rarely receive assistance to help them to maintain these activities or develop new ones as a replacement. I would like to find out about your own experiences of employment and Parkinson's.

- **Research aims**

1) To understand the employment experience and trajectory of younger people with PD

2) To model an intervention to assist people with PD to maintain employment.

- **Objectives**

i) Explore the meaning of occupation for younger people with PD

ii) Identify the aspects of work that may be beneficial to someone with PD

iii) Understand the strategies used for maintaining work by people with PD

iv) Appreciate the decision making process utilized by younger people with PD when choosing to remain in or leave work

Focus Group Prompts

<u>Introductions</u>

- Establish who is in employment

- Details of latest post

- How long ago given up

<u>Employment</u>

Informing employer - What happened when told employer – was any support offered? Any worries about telling employer

What helped you to maintain your employment? Any adaptations

Where did you seek help? Get help from? What would have helped you to stay?

What information or assistance regarding employment would be or have been useful?

Giving up - What influenced your decision making process about giving up? What factors were taken into consideration? Was it your own decision or was it imposed? On reflection do you think you made the right decision? Would you like to have remained in employment? Do you think it is beneficial?

Did you feel like you had a transition period? What did you do with your time immediately following giving up work – did you take on any new roles or activities?

What positive or negative aspects have you found about leaving work? Identity?

<u>Maintaining Leisure Roles</u>

Change in activities – has there been a change in what you do since Parkinson's?

What activities have been given up? What new ones have been taken on? Are you currently undertaking the activities that you want to do?

Why did you give up these activities – what influenced you decision?

What sought of impact has losing these activities made to you and your family?

Do you use mainstream activities or are you using specialist groups? Have you sought or received help to maintain leisure activities?

- Summary
- Thanks
- Contact details of researcher

Appendix I Story Headings

Impact on employment

What was the initial impact on employment

When did you first notice PD affecting your work and in what way

Disclosing your diagnosis

When did you tell your employer and/or colleagues and what was their reaction

Did you have any reservations about disclosing your diagnosis

What made you decide to tell or not to tell

Support and assistance

What support did/do you receive from your employer and colleagues

Did you look elsewhere for help and what help did you get

How successful is/was the support you received

Did you make any changes to the way you work e.g. changing hours

Did/do you use any equipment or have adaptation made and how successful were these changes

Leaving or staying

What factors contributed to your decision to leave or remain in your job?

What was your employers reaction

How did you feel about leaving?

Rights and finances

What was/is your knowledge of you employment rights

Did your employer have any knowledge of the disability discrimination act

Which if any benefits have you claimed

When you left work what was your financial situation (what source did your income come from)?

Were you better/worse off financially?

Did you or your family have to make any changes because of this?

Moving on

Have you experienced applying for jobs since your diagnosis?

Have/did you select particular posts because of your Parkinson's (i.e. part-time)?

What have been potential employer's reactions to your condition?

Work/life balance

What impact did maintaining or leaving your employment have on your leisure activities or family life and how did you address those issues?

If you have left work, what do you do with your time?

Looking back

Retrospectively, is there anything that you think you should or could have done?

Do you think you made the right decisions – would you change anything if you could?

Advice

What tips would you give to someone who has recently been diagnosed regarding managing their employment?

Appendix J Publicity Article in 'The Parkinson' Magazine

Parkinson's and You

Employment web-site for younger people with Parkinson's

Were you diagnosed with Parkinson's before retirement age? Would you like to share your experiences of working whilst having Parkinson's with others? If so, then we need your help!

The 'Parkinson's and You' web-site is the outcome of a research project sponsored by the Parkinson's Disease Society. Some of you may have already been involved in completing the questionnaire and participating in the focus groups. An initial version of this site will be launched in June and can be accessed via a link from the 'new look' PDS site (also being launched in June). We would like to invite you to visit this site 'under construction' and make a contribution……don't worry, we are not asking for money, just your experience!

There are a variety of opportunities for you to make a contribution:

- ❑ Suggest a new section that you feel is missing from the site
- ❑ Suggest a link to a site or a PDS page that you have found useful regarding employment
- ❑ Let us know of a particular technique, strategy or anecdote from your own experience that may be useful to share
- ❑ Or, for those of you with a lot to say, send us your own 'story' of managing employment and Parkinson's.

You have until the end of September to submit your contribution. Then all of the suggestions and experiences will be sorted and added to the site which will then be re-launched in November.

We hope this site will be of great use to younger people who are trying to maintain their employment whilst coping with Parkinson's….. but it can only be as good as the information we receive from you, so please give (your experiences) generously!

Appendix K Questionnaire Results

About the respondents

1) Source of response: questionnaires distributed by PDNS – 29 (48.3%)

                          questionnaires distributed by local groups – 21 (35%)

                          responses from on-line questionnaire – 10 (16.7%)

2) Age of respondents: 31 – 67, mean 51.25, standard deviation 7.19
3) Sex of respondents: 39 male, 21 female
4) Who is the respondent living with? Alone 8 (13.3%), with spouse 31 (51.7%), with parents 3 (5%), with children 4 (6.7%) with spouse and children 14 (23.3%)
5) Age when diagnosed 28 – 59 mean 43.92, standard deviation 7.2
6) Years had Parkinson's 1 – 19, mean 7.2, standard deviation 4.1

Taken a look at the data coming in from the 3 groups –is it similar?

1 way analysis of variance was carried out on the 3 groups in regard to age, gender, years had Parkinson's and age diagnosed, post hoc test used was DUNCAN. There was a significant difference in relation to age and age diagnosed but no difference in the groups regarding the years had Parkinson's or sex.

Employment

7) Category of job – no answer 1 (1.7%), professional occupations 8 (13.3%), managerial and technical occupations 31 (51.7%), skilled occupations 14 (23.3), partly skilled occupations 6 (10%)

8) Currently employed? Yes 23 (38.3%), No 37 (61.7%)

9) Left work due to Parkinson's? Of those currently unemployed (37), 34 of them (92%) left work due to Parkinson's

10) The basis that (people who left work due to Parkinson's) left work (unemployed, and left work due to Parkinson's what were their reasons? – n=34, no answer 4 (11.8%), early retirement 15 44.1%, redundancy 3 (8.8%), ill health retirement 11 (32.4%), mutual agreement 1 (2.9%)

11) Age left employment (n=34, 3 no answers) 30 – 59, mean 48.26, standard deviation 7.29

12) How long following diagnosis left work – in months? (n=34) 1 – 168, mean 43.44, *(3.6 years)*, standard deviation 40.58

13) What age would you have retired? (n=33) 55 – 65, mean 62.27, standard deviation 2.86

14) Years lost in employment due to Parkinson's (n=33) 4 – 35, mean 13.48, standard deviation 7.15

15) Reasons for giving up work answers from 33 people (free text) employers medical requirements 4 (6.7%) psychological reasons (anxiety, depression, stress) 14 (23.3%), physical difficulties (tremor, freezing, fatigue) 27 (45%), lack of understanding from workplace (employer/colleagues) 5 (8.3%)

33 people specified their reasons for giving up and most gave more than one answer.

	Frequency	Percent
No answer	27	45.0
Lack of understanding	1	1.7
Physical difficulties	15	25.0
Psychological difficulties	1	1.7
Psychological difficulties and lack of understanding	2	3.3
Psychological and physical difficulties	9	15.0
Psychological and physical difficulties and lack of understanding	1	1.7
Employers medical requirements	1	1.7
Employers medical requirements and lack of understanding	1	1.7
Employers medical requirements and physical difficulties	1	1.7
Employers medical requirements, physical and psychological difficulties	1	1.7
Total	60	100

16) Would like to have remained employed? Of the 34 who are not in employment and left work due to Parkinson's – No answer – 3 (8.8%) yes 22 (64.7%) no 8 (23.5%), don't know 1 (2.9%)

17) What did you do to fill in your time after leaving work? (free text and some multiple responses) of the 37 who are not in employment and left work for whatever reason. Filled in time with sport 5 (13.5%), further education 5 (13.5.3%), carer 3 (8.1%), travel 4 (10.8%), sedentary hobbies 9 (24.3%), social activities 7 (18.9%) , voluntary activities 12 (32.4%), homemaking 12 (32.4%)

18) How long following diagnosis informed employer (months) 0 – 48, mean 3.63, standard deviation 8.86

19) Did/have adapted working arrangements? No answer 7 (11.7%), yes 26 (43.3%), no 27 (45%)

20) Description of adapted working arrangements (free text and multiple answers) decreased hours 16 (26.7%), special equipment 10 (16.7%), increased help from others 4 (6.7%), changed role 12 (20%)

21) Any benefits of remaining in employment? No answer 3 (5%), yes 45 (75%), no 12 (20%)

22) What benefits (free text and multiple answers) selfesteem/confidence/wellbeing/self-worth 22 (36.7%), making a contribution to society 12 (20%), physical fitness 9 (15%), mental stimulation 10 (16.7%), social contact 16 (26.7%), promotion of PD 3 (5%), distraction from condition and structure to the day 10 (16.7%), financial 22 (36.7%)

23) Sought assistance to remain in employment? No answer 1 (1.7%), yes 24 (40%), no 35 (58.3%)

24) Where looked for assistance? (free text transformed into one variable) of those 24 who responded that they had sought assistance, No answer1 (4.2%), PDS 4 (16.7%), Union 2 (8.3%), GP/Cons 2 (8.3%), employer/HR/colleagues 6 (25%), DEA/Job Centre 3 (12.5%), occupational therapist 2 (8.3%), other (friends, financial consultants or more than one source) 4 (16.7%)

25) Did you receive any assistance? No answer 5 (8.3%), yes 22 (36.7%), no 33 (55%)

26) Who provided the assistance?(one variable of the 22 who answered that they had received assistance,)No answer 1 (4.5%) PDS Welfare officer 2 (9.1%), Employer/HR/Colleagues 15 (68.2%), GP/Cons 1 (4.5%), DEA 2 (9.1%), occupational therapist 1 (4.5%)

27) How did you find out about the assistance? (one variable of the 22 who answered that they had received assistance) No answer 8 (36.4%), PDS Welfare officer 1 (4.5%), Union 1 (4.5%), employer/HR 10 (45.5%), healthcare professionals 1 (4.5%), GP/Cons 1 (4.5%)

28) What did they do for you? (one variable of the 22 who answered that they had received assistance) No answer (13.6%) provided physical assistance 1 (4.5%), decreased hours 1 (4.5%), changed working arrangements/role 6 (27.3%), provided equipment 3 (13.6%), helped to make an informed choice about staying or leaving 1 (4.5 %), provided financial assistance 2 (9.1%), medical assistance 1 (4.5%), more than one area of assistance 4 (18.2%)

29) How successful was it? 22 respondents No answer 3 (13.6%), very 12 (54.5%), moderately 6 (27.3%), not at all 1 (4.5%)

30) Would you like to have received assistance? Of those who didn't receive assistance (33), No answer 6 (18.2%) Yes 15 (45.5%), No 12 (36.4%)

NB. Some respondents contradicted themselves, so in these cases the questionnaires were studied and the most likely answer gathered e.g. a respondent wrote that they had received help from the PDS welfare officer regarding maintaining their employment and then immediately underneath ticked the 'no' box when responding to 'did you receive any assistance in helping you to remain in employment' therefore this was entered as 'yes'.

Leisure

The activities listed by respondents were converted into groups of activities to enable analysis. The groups were:

- Sport – including football, running, walking, gym attendance, golf

- Voluntary work – including charity, church and school groups

- DIY/Gardening – including decorating and allotments

- Social activities – including dining out and meeting friends

- Sedentary hobbies – including computer based activities such as family tree research and reading

- Travelling – including day trips, short breaks and holidays

- Creative activities – including craft work and painting

- Further education – including distance learning and night classes

31) Prior to Parkinson's how many hours per week were spent carrying out activities?
   - Sport - mean number of hours 4.95 standard deviation 5.79 max 28

   - Voluntary work – mean 0.40 standard deviation 1.42 max 7

   - DIY/Gardening – mean 2.2 standard deviation 3.18 max 12

- Social activities – mean 4.12 standard deviation 5.53 max 27

- Sedentary hobbies – mean 1.27 standard deviation 3.26 max 14

- Travelling – mean 1.6 standard deviation 3.57 max 15

- Creative activities – mean 2.37 standard deviation 4.75 max 21

- Further education – mean 0.48 standard deviation 1.69 max 10

Total hours spent per person on leisure activities prior to Parkinson's – mean = 17.46, standard deviation 11.79 max 55

As clinical experience and literature indicated that people with Parkinson's became less physically active and more socially withdrawn following diagnosis, the activities listed by the respondents were categorised into active (sporting) or sedentary (computer based) activities and again into social (with other people) or solitary (carried out alone) activities.

32) Prior to Parkinson's hours spent carrying out the following categories of leisure activities
- Active social - mean 4.77 standard deviation 5.36 max 28 median 3 hours

- Active solitary - mean 5.78 standard deviation 6.09 max 27 median 4 hours

- Sedentary social - mean 3.75 standard deviation 6.28 max 29 median 0 hours

- Sedentary solitary - mean 3.15 standard deviation 5.68 max 21 median 0 hours

33) Post Parkinson's how many hours per week spent carrying out leisure activities?
- Sport - mean number of hours 1.98 standard deviation 3.49 max 21

- Voluntary work – mean 1.02 standard deviation 2.87 max 17

- DIY/Gardening – mean 1.58 standard deviation 4.05 max 22

- Social activities – mean   1.37 standard deviation 3.27 max 18

- Sedentary hobbies – mean 7.30 standard deviation 11.14 max 49

- Travelling – mean 1.23 standard deviation 3.74 max 20

- Creative activities – mean 2.53 standard deviation 5.59 max 23

- Further education – mean 0.1 standard deviation 0.57 max 4

Post Parkinson's number of hours spent on leisure activities in total mean – 17.1, standard deviation 14.46, max 57

The paired sample t-test was carried out and found no significant difference between pre and post Parkinson's in total hours spent on leisure activities. Again, The Wilcoxon test again found no significant difference, whilst medians change it was not significant due to the spread of data.

NB. Some respondents had filled in their employment in this section. Specific occupations were removed however voluntary work was left in as that could be seen as a social activity. On a similar note home-making activities that could be described as leisure were retained.

Is there a difference in the type of activities pre and post Parkinson's? When comparing the difference between activities pre and post Parkinson's (t-test) there was a significant difference in sedentary hobbies, social activities and sport. An increase in sedentary hobbies from 1.27 to 7.3 hours, a decrease in social activities from 4.12 to 1.37 and a decrease in sport from 4.95 to 1.98

34) Post Parkinson's hours spent carrying out the following categories of leisure activities
- Active social - mean 2.37 standard deviation 4.95 max 26 median 0

- Active solitary - mean 3.68 standard deviation 6.08 max 24 median 0

- Sedentary social - mean 2.75 standard deviation 5 max 21 median 0

- Sedentary solitary - mean 9.18 standard deviation 11.21 max 49 median 6.5

35) What was the overall effect that Parkinson's has had on leisure activities?

No answer1 (1.7%), no effect 2 (3.3%), positive effect 3 (5%), minimal negative effect, 5 (8.3%), gradual curtailment 26 (43.3%), ceased most or all activities 22 (36.7%), positive and negative aspects 1 (1.7%)

36) What were the reasons for giving up activities? (free text, separate variables, some multiple answers, not everyone answered) Physical reasons (fatigue, stamina, tremor) 49 (81.7%) psychological (embarrassment, motivation, confidence) 20 (33.3%), other (transport, time, financial) 8 (13.3%)

NB. Some respondents wrote the reasons for giving up the activities rather than the overall effect. So some degree of interpretation was used in these responses.

37) What type of activity was given up? (Free text, separate variables, some multiple answers, not everyone answered) The activities listed by respondents were put into the same categories as previous questions. Sport 41 (68.3%), DIY/home/garden 6 (10%), voluntary activities 3 (5%) social activities 16 (26.7%), sedentary hobbies 3 (5%), travelling 5 (8.3%), creative activities 6 (10%), further education 1 (1.7%).

38) What category of activity was given up? (Separate variables, not all respondents answered). Active social 39 (65%), active solitary 19 (31.7%), sedentary social 12 (20%), sedentary solitary 7 (11.7%), no activities given up 10 (16.3%)

39) What new activities have been taken up? (Free text, separate variables, some multiple answers, not everyone answered). Sport 15 (25%), voluntary work 11 (18.3%), home/DIY/gardening 0 , social activities 6 (10%), sedentary hobbies 15 (25%), travelling 0, creative activities 4 (6.7%), further-education 2 (3.3%), none 13 (21.7) NB this is not a 'no-answer'

NB. When classifying new activities taken up, if more than one was listed then the one the respondent spent the most time on was classified.

40) What category of activity has been taken up? active social 13 (21.7%), active solitary 5 (8.3%), sedentary social 11 (18.3%), sedentary solitary 14 (23.3%), none 4 (6.7%)

41) Did you seek assistance to maintain leisure activities? No answer 3 (5%), yes 10 (16.7%), no 47 (78.3%)

42) Did you receive any assistance? No answer 5 (8.3%), yes 12 (20%), no 43 (71.7%)

43) Where did you look for assistance? (of those 10 who sought assistance)No answer 1 (10%) GP 4 (40%), family/friends1 (10%), leisure/sports club 1 (10%), social/support services 2 (20%), more than 1 source 1 (10%)

44) Who provided the assistance? (of those 12 who answered that they had received assistance) No answer 1 (8.3%), GP 2 (16.7%), family/friends 1 (8.3%), leisure/sports club 5 (41.7%), physiotherapist 1 (8.3%), social/support services 2 (16.7%)

45) How did you find out about it? (of the 12 who said that they had received assistance) No answer 2 (16.7%) sports club offered 2 (16.7%), PDS 3 (25%), GP 2 (16.7%), physio/occupational therapist 1 (8.3%), friends 2 (16.7%)

46) What did they do? (of the 12 who said that they had received assistance) Adjusted activity 1 (8.3%), provided support 4 (33.3%), financial help 3 (25%), exercises/physical adjustment 1 (8.3%), directed towards an activity1 (8.3%), provided transport 1 (8.3%), medical intervention 1 (8.3%)

47) Was it successful? (of the 12 who said that they had received assistance) No answer 2 (16.7), yes 7 (58.3%), no 3 (25%)

48) Would you like any assistance to maintain leisure activities? (of the 43 who answered that they had not received any assistance) No answer 7 (16.3%), yes 19 (44.2%) , no 17 (39.5%)

49) Any benefits in maintaining leisure activities? No answer 5 (8.3%), yes 52 (86.7%), no 3 (5%)

50) What are the benefits of maintaining leisure activities? (free text, separate variables, multiple responses, not all answered) self esteem/confidence/well-being/self-worth 16 (26.7%), physical fitness 33 (55%), mental stimulation 25 (41.7%), promotion of Parkinson's 3 (5%), social contact 17 (28.3%), other 3 (5%)

Self –management

51) Have you been offered a self-management programme? No answer 3 (5%), yes 18 (30%), no 39 (65%)

52) Were you offered one and declined? Of the 18 who said that they had been offered a programme - No answer 4 (22.2%), yes 4 (22.2%), no 10 (55.6%)

53) Why did you decline? Of the 4 who had been offered a programme but had declined No answer 0 , wrong time 2 (50%), wrong location 1 (25%), currently don't need it 1 (25%)

Description of the programme

54) How many sessions? Of the 14 people who had been offered a programme but had not declined - No answer 6 (42.9%), three sessions 1 (7.1%), six sessions 6 (42.%), ten sessions 1 (7.1%) mean = 3.5 sessions

55) How long were the sessions? No answer 2 (14.3%), 1 hour 2 (14.3%), 2 hours 4 (28.6%), 3 hours 4 (28.6%) , 6 hours 1 (7.1), 7 hours 1 (7.1)

56) Where held? No answer 3 (21.4%), hospital 8 (57.1%), hotel 1 (7.1%), community facility 2 (14.3%)

57) What topics were covered (free text, separate variables, multiple responses). Physical fitness 8 (13.3%), emotional impact 6 (10%), managing the condition 7(11.7%), diet 5 (8.3%), medication 1 (1.7%), speech 3 (5%), scientific advances 4 (6.7%)

58) Which professionals were involved? (free text, separate variables, multiple responses) physiotherapist 8 (13.3%), occupational therapist 5 (8.3%), SLT 2 (3.3%), nurse 6 (10%), dietician 2 (3.3%), PDS 4 (6.7%)

59) Any sessions on employment and leisure? Of the 14 people who had been offered a programme but had not declined No answer 1 (7.1%), yes 9 (64.3%), no 4 (28.6%)

60) Describe the employment and leisure sessions, (free text, 1 variable) encouraged to keep going 3 (5%), biased towards retired people 1 (1.7%), benefits2 (3.3%), communication with employers 1 (1.7%)

61) Did the programme benefit you? No answer 1 (7.1%), yes 13 (92.9%), no – 0

62) In what way ? (free text, 1 variable)no answer 2 (14.3%), sharing with other people who have pd 5 (35.7%), contact with professionals 1 (7.1%), increased knowledge 2 (14.3%) 'all three' 4 (28.6%)

63) Most useful session. No answer 3 (28.4%), falls/balance 2 (14.3%), group discussion1 (7.1%), employment 1 (7.1%), benefits 1 (7.1%), relaxation 2 (14.3%), all useful 4 (28.6%)

64) Anything missing from the programme? No answer 6 (42.9%), nothing 3 (21.4%), employment 3 (21.4%), follow up session 1 (7.1%), more social contact with participants 1 (7.1%)

65) Would you like to attend a self-management programme? Of those who were not offered a programme No answer2 (5.1%), yes 24 (61.5%), no 13 (33.3%)

66) In what way would you benefit from attending a self-management programme? (Of those who were not offered a programme – free text, separate variables, multiple answers) meet other people young people with PD 3 (7.7%), increase confidence 2 (5.1%), increase knowledge/advice/information 13 (33.3%), change perspective 4 (10.3%), access to new activities 3 (7.7%), increased independence 6 (15.4%)

67) Why would you not like to attend a self-management programme? (Of those who said they would not like to attend, free text, one variable) No answer 1 (7.7%), managing OK without 6 (46.2%), don't like the sound of it 4 (30.8%), don't want to focus on condition 1 (7.7%), too late to be of any use 1 (7.7%)
NB. Some respondents expressed strongly that they didn't like the sound of a self-management programme, calling it 'patronising' or 'simplistic.' Other respondents stated that they would only attend a younger person's programme.

68) Where do you get information from regarding PD? (separate variables) GP 18 (30%), PDNS/welfare officer 35 (58.3%), consultant 11 (18.3%), other health professionals 2 (3.3%), PDS publications/web-sites 13 (21.7%), non-PDS publications 11 (18.3%), no-one/no source 1 (1.7%)

Internet questions

69) Have ready access to internet? Yes 54 (90%), no 6 (10%)

70) Where do you access the internet? No answer 4 (6.7%), home 53 (88.3%) friends/family 1 (1.7%), further education establishment/library 2 (3.3%)

NB. Only recorded the first response as many people had access to the internet at home and work. This question should have had option 'if unable to access the internet, then skip this section' however this was only the case for one respondent.

71) Ever used the internet to access healthcare information? No answer2 (3.3%), yes 44 (73.3%), no 14 (23.3%)

72) Ever used it to access information on Parkinson's? No answer 3 (5%), yes 47 (78.3%), no 10 (16.7%)

73) What type of information about Parkinson's have you accessed? (separate variables) drugs/surgery 42 (70%), research 28 (46.7%), PDS information 17 (28.3%), symptoms/prognosis 22 (36.7%), management of condition 17 (28.3%), other 6 (10%)

74) Ever tried to access employment/leisure information? No answer 1 (1.7%), yes 15 (25%), no 44 (73.3%)

75) Did you find any information on employment and leisure? (of the 15 who tried to access information on employment and leisure) No answer 3 (20%), yes (40%), no 6 (40%)

76) As you have not tried to access information about employment and leisure, can you describe your reasons? (of the 44 who said they had not tried to access info on employment and leisure) No answer 26 (59.1%), don't need any information currently 7 (15.9%), don't know where to look 4 (9.1%), not enough concentration/energy 1 (2.3%), didn't occur to me to look 4 (9.1%), get information from current sources 2 (4.5%)

77) How satisfied were you with the level of information re. Leisure? (of those 15 who had sought information) No answer 6 (40%), moderately 5 (33.3%), not at all 4 (26.7%)

78) How satisfied were you with the level of information re. Employment? (of those 15 who had sought information) No answer 6 (40%), moderately 6 (40%), not at all 3 (20%)

79) Would you access employment/leisure information if it was easily available on the internet? No answer 5 (8.3%), yes 42 (70%), no 13 (21.7%)

80) What sort of information re employment/leisure would you like to see on the internet? No answer 25 (41.7%), benefits 4 (6.7%), employment law and rights in lay terms 7 (11.7%), adaptations to workplace 2 (3.3%), information on gaining employment 5 (8.3%), groups and locations 6 (10%), positive examples and case studies 4 (6.7%), adaptations to leisure activities 1 (1.7%), accessible environments 2 (3.3%)

81) Have you ever used an internet support group? No answer 2 (3.3%), yes 7 (11.7%), no 51 (85%)

82) Can you describe it? (of the 7 who said that they had accessed one)No answer 1 (14.3%), Parkinson's related chat room 2 (28.6%), Parkinson's related chat room (US) 4 (57.1%)

83) In what way have you benefited from using it? (of the 7 who said they had accessed one) No answer 3 (42.9%), none 1 (14.3%), different perspective 1 (14.3%), too US focussed 2 (28.6%)

Appendix L Collated Stories

1)Impact on employment

1a)What was the initial impact on employment

S1) Unable to, concentrate and carry out client interviews, memory loss
and confusion also impacted on my ability to carry out my duties

S2) None

S3) An inability to write legible notes. A fatigue that was is very
draining. A tremor which gets worse the more anxious I get.

S4) very little at first- just the need to adjust to the fact that my
career and life ahead was uncertain. i have largely put my head down and
tried to ignore the fact i had PD. However, just recently - adjustments to
medication treatment may change all of this. My employer and clients are not
aware i have PD. I'm still in the closett.

S5) The impact has been limited so far, since I was diagnosed early and
didn't want to tell anyone at work immediately until I understood more about
Parkinson's myself. I need to be able to drive and I am worried that this
may be one of the biggest factors affecting my ability to get to work and to
do my job.

S6) Initially there was no impact on employment. My symptoms weren't so
prevalent.

S7) My arms started to stiffen, making typing increasingly difficult.

S8) Initially I took sick leave to get my head together. It wasnt the
physical factors more the emotional impact.When I did return I was sent to
Occupational Health on the morning of my return and a doctor who didnt meet
me banned me from driving during working hrs!
Eventually I got control myself, regained my dignity and 'hey presto!'
people changed toward me at work. I believe its because I am more aware of
my employment rights and aware of my symptoms. 'Knowledge is power!'

S9) problem in writing

S10) Very little

S11) Initially PD had litttle effect although concentration was becoming more difficult

S12) initially I continued to work. I found that I was having a tough time working up to my own standards. I gradually worked at decreasing my stress and workload by shifting from a special education class to a Resource Teacher program and then down to elementary from middle school.

S13) I was reprimanded for being too slow on my checkout. I knew I was getting slower but did not know why

S14) Tiredness, increased stress. Inability to press buttons on machinery (which was required for the driving process)and loss of balance.

S15) There was no initial impact as I did not disclose my condition but kept it to very close family and friends

S16) Unanswered

S17) How the hell am I going to do my job now

S18) Fear! Most employers think that you will immediately start shaking and falling about. They often think that your mental capabilities are automatically affected. When I needed to change jobs (moved area) because I was not applying for management positions (I felt I wanted less pressure) and I explained why , although given an interview, I sensed that I was not going to get the job.

S19) I had been in this post about four years My position required 150% dedication and it was obvious that I could not be carried.

S20) I found difficulty speaking when stressed or tired. I also had some difficulties in walking. Clients were puzzled. My 2 business partners panicked.

1b)When did you first notice PD affecting your work and in what way

S1)Somewhere in or about 1998 depression and panic attacks were very severe, memory, concentration and social skills all suffered

S2) Difficulty handwriting which I first put down to arthritis, then carpal tunnel. I am dependent upon a compute & e-mail which is not too much of a problem. Otherwise, it affects me mainly with tiredness and memory loss but that is probably because I do not sleep well.

S3) Writing became smaller about four years ago which meant illegible notes. I can't always read what I've written my self.

S4) First effect was the loss of fluent movement in my left hand for touch typing. I also try to avoid addressing public meetings,presentations etc. Five years on - difficult to work at the pace and work load once could. i find it hard to focus on things to complete them.

S5) Slowness in my left hand affected my computer keyboard skills. I keep holding keys down longer than I should and the co-ordination between left anf right hand is difficult.

S6) Probably about 4 years after diagnosis. Inability to shuffle paper ie, letter filing, sorting through reports,no longer dextrous. Parkinsons affects my left side. Later I found it difficult to use both hands when using computer. I was then having difficulty moving around the reception area without "getting in other peoples way".

S7) As above. After a time my walking became a problem.

 S8) When I was 'slow' in using my keyboard. Unfortunatley my line manager sits opposit and would stare at me or worse still make comments. My writing became small also.I began to experience problems walking and negotiating my way around the office. I had problems getting to work for the 8.30 start time.

S9) my slowness and problem using my right hand and i was tired veryquickly

S10) My job involves driving long distances and 18 months after being diagnosed I felt I ought to inform my employer re driving situation in case of an accident. I was finding long journeys difficult and allowed journey time to nap in a service station

S11) I had to hand write between 50 & 100 cheques at the end of the month and it was getting more difficult to be consistent when I had always had reasonably ledgible hand-writing.

S12) probably the first thing I noticed at work was that my handwriting became increasing difficult to read, partly due to the fact that it was getting smaller, but also because I was beginning to experience tremor in my right hand. I was also having a difficult time walking(I had a robotic look to my gait) and was extremely fatigued, both during the day and at home.

S13) My actions were becoming clumsy and I was very tierd at the end of my shift.This built up over a period of 18 months

S14) Autumn 1994 when I knew there would be a lot of long shifts and stressful situations over the next 2-3 months during 'leaf fall'.

S15) I started to feel that I was not able to do certain tasks that were fiddly or when I was being watched doing a particular skill that required dexterity - infants shirt buttons, threading needles, doing up unruly shoe laces, etc. this was probably about three years ago but more noticeable to me than others.

S16) 4 years ago, my right hand slow and my fingers are not as resonsive as used to be. My handwritng is nearly illegible. Stess makes symptoms worse.

S17) I was getting cramp in my left leg and could not separate the delivery notes with my left hand

S18) My writing became very small. Having to use the computer, if I accidentally allowed my hands to rest over the keyboard whilst composing my letters etc, I would end up with a line of //// or aaa's!

Sitting for a long while also used to make me very stiff and uncomfortable.

Probably the most stressful was the continual pain in my right shoulder (which had been treated as repetitive strain injury).

S19) In Spring 1994 I realised that I was making typing mistakes and my handwriting, when taking telephone messages, was getting smaller and smaller. I was unable to drum the fingers of my right hand on the table.

S20) After a long day, I could hardly speak. I had pains in the back of my neck. My typing slowed down considerably.

2)Disclosing your diagnosis

2a)When did you tell your employer and/or colleagues and what was their reaction

S1)About one month after I was diagnosed, shock that someone so

young could have PD. All levels of management were very supportative

S2) Told my employer upon diagnosis after Union advice & becasue of insurance implications etc. It is a large company that is good on confidentiality & equal opps. Colleagues have been very supportive. Telling my (2) teams was more difficult and recently, after some concerns from them I discussed how it affected me with one team. The other team I manage does not seem bothered but will sometimes offer help I do not need (eg with carrying things). Its difficult to describe the areas it affects & doesn't affect me.

S3) I told my employer by phone as soon as I got back from my Neurology appointment and asked her to tell the rest of the team. They have been brilliant and extremely supportive.

S4) Haven't yet.

S5) I told my boss, immediate colleagues and the HR people eight months after diagnosis. That is only in the last few weeks, but initial reactions have been supportive.

S6) I told my colleagues and practice manager straight away as they knew I was going to see a neurologist and were quite concerned. Disbelief from my colleagues. My practice manager was sympathetic and didn't go into further detail about my job as I was still fully capable. She did say she wouldn't tell other members of staff, if I wanted anyone to kmow I should tell them. Well I am a fairly private person so a lot of people didn't find out for a number of years. I did however presume that the manager would inform the doctors in the practice. For 6 years I continued to work there and none of the four doctors ever mentioned it or asked how I was.

S7) As they had noticed something badly amiss, they were relieved when I gave them my diagnosis. I have received nothing but understanding and their instinting support

S8) Ive been pretty open from the outset.I think response depends upon agenda. In generall most colleagues are very supportive.Admin particularly . One worker would defend me to the last! Occupational health have turned out to be very useful, directing my manager to be flexible in working time and in allowing me to work from home.

S9) he was sad and asked me to take rest and go toa gooddoctor

S10) 18 months after being diagnosed I told my employer and asked that they replace my existing co car with an automatic

Co attitude exemplary - arranged new car and made it clear that I should keep them informed of any change in condition. Colleagues were generally sympathetic and helpful

S11) My employer was a long term friend and I told him immediately. He offered his commiserations, wished me well and asked me to make my own decisions regarding methods of work.

S12) I was upfront with my employers and colleagues as soon as I found out what I had. The diagnosis took about a year to accomplish, and everyone could see that there was something haywire with me. All of my coworkers were supportive and stunned that I somehow had gotten this "old persons" disease.

S13) I told them straight away. their reactions were varied. My employers did not have much information on PD and did not seem to want to know about it.My colleagues were more curious but did not go into it very extensivly

S14) Immediately after diagnosis. They requested a BUPA examination to consider my fitness to drive and to carry out my duties.

S15) I told my Head teacher approximately 5years ago. She was extremely helpful in reassuring me that it would not affect my position.

The other 'teaching staff' were informed but no reference was made. Gradually (as no-one seeems able to keep anything to themselves, whatever the subject!) the other part-time staff and support staff have heard of my condition.

No- one has been anything less than sympathetic or tried to be helpful - unfortunately, even when I can cope with the task in hand there is always someone who thinks they can relieve me, mostly they mean well but sometimes it is so infuriating to have things taken away from you because they deem I am not capable.

S16) Straight away, as I previously had an operation for frozen shoulder.

S17) On diagnosis, work colleagues were very supportive, occupational nurse nearly had a coronary until i got the letter from the DVLA saying I was fit to drive

S18) Not until about a year after I was employed as an office manager. Shocked! But very sensitive. Always allowed me time to go to the Drs and looked after me when I had the odd wobbly. Read up on it and made allowances for the writing.

S19) I informed my employer and colleagues the day after my diagnosis, 24 September 1994 and they were incredibly sympathetic and supportive.

S20) I told my 2 business partners the day after I was diagnosed. They panicked. THey assumed that I would quickly become aliability and that no clients would want to hire me.

2b)Did you have any reservations about disclosing your diagnosis

S1)some embarassment mostly due to misunderstanding what PD is.

S2) Yes, of course. Privately peoples reactions had been so different. From 'What's that?' from one sister to a huge hug (we are not tactile!) & tears from another.

S3) None what so ever.

S4) Yes and still do.

S5) Yes, although I know that there is protection under the Disability Discrimination Act, I was concerned that there were potential redundancies on the horizon and my disability may count against me. If an employer wanted to get rid of someone with a disability, they could give another reason.
I had also heard other people say that their colleagues have made life difficult, by resenting any extra support they get as a disabled person. This was a worry to me.

S6)no

S7)None

S8) Yes. I feared the worst that I may lose my job or status. I also thought..." Its none of their buisness anyway!"

S9) unanswered

S10) No

S11) no

S12) I didn't have any reservations about disclosing my diagnosis. I always believed in letting people know for two reasons: first, you never know who has a family member with PD and can help you out with information and contacts, second, if you don't let people know, they jump to the strangest conclusions, like the people at the little league who thought I was becoming an alcoholic due to my bumbling, stumbling gait!

S13) No none at all.

S14) Yes once disclosed there was no going back!!!

S15) I was anxious about revealing my problems, at the time I was diagnosed no- one would have guessed as it was not obvious. I worried that I might be more closely scrutinised and even have my hours reduced or asked to leave. I loved my job and put a lot of time and effort into it.

S16)No

S17) no I had to tell them by law

S18) Yes. I hate telling people, I sometimes feel like a freak.   When I am having a good day, nobody would know, but when I shut down I find it very hard to hide it now. I don't tell them unless there is a health questionnaire.

S19) : I had no reservations whatsoever. This was the the time when
the school SATs were being designed. Goldsmiths Cllge won the bid to
devise the SATs for Design & Technology and I had been offered the post of
Administrator. There were 7 teachers and lecturers, headhunted from all
over the British Isles and I was the sole administrator. My work involved
minuting meetings in the office, attending meetings in London with the 4
other Unis (English, Science, History, Maths); contacting schools
throughout the country; writing in Welsh. I was given complete freedom to
order equipment etc.; my salary was excellent and I repaid their trust in
me by working hard.

S20) Yes, for the reasons above.

2c)What made you decide to tell or not to tell

S1)The 'not knowing' element. Not knowing what was wrong generated its own distinct form of social isolation. The relief of having the not knowing element removed was worth sharing, the wondering, speculating yet never knowing what the problem is was gone. It took about a month for the relief of knowing what was wrong and for the diagnosis to sink in after which time I felt it only right to inform my colleagues.

S2) Its less stressful being honest and a determination to support the social model of disability.

S3) I told them because, I feel that if I was having a bad day then they wouldn't be critical. Also when I told my PDNS, Richard, he said that it was a good idea.

S4) Hard to predict the reaction by the employer and clients to knowledge of my predicament. I accept that it will happen one day.

S5) Colleagues noticed that my walking had deteriorated and asked whether I had hurt my leg. I didn't want to lie, so I just put them off at first, but then I decided it would be best to tell them. Colleagues were shocked, but very supportive, at least verbally. My Boss said the right things and the HR people were also sympathetic. Time will tell how this translates into action.

S6) The people concerned were my friends so already knew there was a problem.

S7) I felt they had a right to know, especially when they were so worried

S8) Because I didnt want to hide from people. Also I am who I am!

S9)Unanswered

S10) At first I didn't see that it had any relevance but later felt it was the right thing to do especially re driving a co car

S11) No reason not to tell.

S12) It was so obvious that something was wrong, what would have been the point

S13) I knew I could not go on as I was.

S14) Fear of causing an accident at work. Can you imagine the consequences?

S15) Basically honesty is the best policy. I had, and still do have, the utmost respect for the Headteacher I told. (she has now left the school where I work)She was more than just

a headteacher to all her staff.

S16) Did not have an option as I had been seen by an Occupational Therapist ragarding my shoulder.

S17) the law

S18) Just in case I needed some help. When you start taking different medications, they can sometimes have an adverse affect. I reacted very badly to an agonist and ended up collapsing at work.

S19) I knew immediately that I would be unable to provide the level of
service that the position required and if I did not act quickly then I
would put at risk all the excellent work that I had achieved so far.

S20) They knew someting was wrong -and I decided to exert control over
events.

3)Support and assistance

3a)What support did/do you receive from your employer and colleagues

S1)Employment support, access to work guidance and a very flexible
approach to the hours I worked, starting later and finishing earlier.

S2) OK; I got a laptop

S3) Excellent support from my work colleagues and my Head OT.

S4)Unanswered

S5) The offer of help is there if/when I need it, although there are no
concrete arrangements in place yet. I have asked for a monitoring process to

be set up so that I can have regular meetings with HR and tell them about how things are going, as well as having the opportunity to ask for specific help. The private health cover provided by my employer does not include chronic illnesses, including PD, which is disappointing. When I mentioned this, HR said that that was the case with all of these types of policy.

S6) I received lots of support from my immediate colleagues, however the workload was very intense. No-one other than the doctors or practice manager could do anything about that, but nothing was done.

S7) Their unstinting supporrt has been quite astounding.

S8) Support is more forthcomming as time goes on. My colleagues and employers are excellent. I have flexible working arrangements regarding time and work venue. I get assistance if I'm going to travel long distances ie I take the train not driving. I receive time off to attend appointments; hospital; gp; physio.

S9)unanswered

S10) an automatic car also fitted with a modification to allow use of indicator from both sides -- I could have had further modifications but do not require them. My manager's first question is always 'how are you' he encourages me to miss non essential meetings if they involve too much travelling. I have also been actively encouraged to use the train if necessary. I am never hassled re producing more work (although I am aware I've slowed down)colleagues usually offer to carry bags/trays etc - when they remember!

S11) I was allowed to make my own arrangements much as I had done before diagnosis. I opened the office at 8:30 and left between 16:00 & 18:00. With new IT equipment the work load was changing anyway.

S12) Colleagues offered help with all kinds of tasks that I had to do. My bosses couldn't have been more helpful, allowing me to tone down my stress level by changing jobs (all within the teaching profession) 3 times in a 5 year period. My last year of work was in a position that I created out of thin air, teaching kids to use Microsoft Office, running a school video production class and acting as the school district videographer. It killed me to give that job up!

S13) I was given a lighter job to do, and after a long struggle and a letter from my GP given a chair. I have also cut my hours to 20 a week. A couple of my workmates are very supportive the rest tend to ignore it.

S14) Only one person was panicked. A colleague considered I should stop everything to do with the railway immediately and leave. Everyone else was sympathic and looked at ways of helping me to continue working in some other way.

S15) I have recently had a 'bad spell' and at the end of the summer term had to have time off from work. Generally colleagues were concerned for me - I found it extremely difficult admitting defeat, became very depressed about my ability to do the job and worried that there would be place for me at school. Since I had/have some seniority and responsibility it was all the more difficult to contemplate having to give up work.

S16) I have been supplie with and trained to use Dragon Naturally Speaking (voice recognition software).

S17) work colleagues were very supportive

S18) They have been very sympathetic, but never patronising. I work alongside everyone as an equal and try very hard not to let it take over my life.

S19) Their support was immediate - a temp was brought in who would
work under me whilst my medication was being sorted. Unfortunately I was
going through the menopause at the same time and could not cope with that
and PD.

S20)None

3b)Did you look elsewhere for help and what help did you get

S1) Disability Action, in the form of access to work and Employment
support

S2) No

S3) My PDNS, my GP and my Occy Health councillor have supported me,
listened to me, wiped my tears and generally "been there" when I needed
them. Job centre plus are amazing. They are giving me funding for a support
worker. The support worker will:- write my notes, drive in the PM, adjust
equipment and carry equipment up/down stairs. The post is out to ad at the
moment, closing date 13/08.

S4)Unanswered

S5) Friends with PD I have made since my diagnosis have been very helpful in steering me towards the kind of things that may be avaiable and sources of help. I have not used any of these yet, but I am aware of the access to work programme in particular that I think will be useful going forward.

S6) Elsewhere: No I didn't look elsewhere. I was looking forward to early N retirememt

S7) My GP and PD Soecialist nurse have been brilliant as as the consulltant and local Occupational Therapy lady.

S8) PDS Welfare Rights Oficer. My husband and I attended a Welfare Rights day in Manchester. He gave us advice about claiming disability allowance.He followed this up on the telephone.

S9)unanswered

S10)no

S11)no

S12) Elsewhere: I tried to find a support group for early onset Parkinsons patients without success. I found the Parkinsons Information Exchange Network on the internet. I bought Linda Herman's book, When Parkinsons Strikes Early. I joined the Parkinsons support group in Sacramento, California

S13) Yes I spoke to a lady from the Scottish Resource Centre when I was very down about diagnosis and she helped me come to terms with it.

S14) PDS Helpline were wonderful. especially David Schon and John Bucknel.

S15) Yes. I contacted Suzanne Tucker, the local P.D. community support, who also suggested that I contact Jacqui Handley the P.D. Nurse for this area. Suzanne was helpful and promised finding out more info. for me. Jacqui saw me at one of her clinics and ran through a few health checks with me and contacted my GP.

S16) Acess to Work (as above)

S17) PDS loads of help from my local branch

S18) Employment departments are not always helpful, and try to offer menial jobs. Just because I wanted less hours, did not necessarily mean that I was not capable of doing my job properly.

Success: The support I have with my present employer is excellent. I have tried to get help with LDA in order to reduce my working week, but that attempt was unsuccessful.

S19) I applied for retirement on the grounds of ill health and this was granted immediately; I was given a lump sum with twelve added years and a pension. I was in College accommodation, which went with the job, and was given time to buy somewhere.

S20)Speech Therapy has been very helpful

3c)How successful is/was the support you received

S1)Very, the support enabled me to remain at work, perhaps to years longer than I would have, had I not received the support.

S2) Unanswered

S3) Don't know yet, support worker not in situ yet.

S4)Unanswered

S5) Not in place yet, so I cannot comment

S6)Unanswered

S7) Very. I feel more confident, especially during the bad times.

S8) I was succesful in my claim and its made a massive difference in my mobility.

S9)unanswered

S10)unanswered

S11)unanswered

S12) Success: No luck finding an early onset group. Even tried to start my own without success. The PIEN list is a e-mail support group that is very helpful, both as a source of information regarding PD medications, but also to give a PWP someone to "talk to." Linda's book was very helpful both for the peek into my future and as a source of contact info. The group is nice but it's an hour from   my home so it's not exactly accessible.

S13) It helped me put my illness into perpective as I felt my life had ended at that time.

S14) Very as I left AMEC Rail with early retirement due to ill health and am now receiving DLA and Incapacity Allowance. My wife has carers allowance.

S15) Sue filled in the DLA forms (not an easy task - took a minimum of 6.5 hours, and that was after I had scanned the questions, thought about them and given fairly full answers to kick off with) I did not realise at the time that all the effort may only be worth £15 a week. I might have thought twice about it if I had. Not wanting to be churlish or 'looking a gift horse in the mouth' the whole experience of having to write down in detail how long it takes you to cut your toenails, walk a crooked mile, and go to the loo did not leave me feeling wonderful about myself or the future!

S16) Partly. I have to share my office with a colleague which sometmes makes using Dragon difficult.

S17) excellent

S18) The support I have with my present employer is excellent. I have tried to get help with LDA in order to reduce my working week, but that attempt was unsuccessful.

S19) Very successful

S20)Unanswered

3d)Did you make any changes to the way you work e.g. changing hours

S1) I no longer had any contact with the members of the public. During
the last two years an in-house agreement with my manager allowed me to come
and do as I as I deemed necessary. The last year I worked between 9am to
2pm, some days I would get in to the office at 10am and leave at 12.30pm,
other days I would work 9am -2pm, WE've had to tighten the financial belt
considerably.

S2) Some of my work can be done from home anyway which is helpful. My
hours are within my own control and (as a sort of outpost from Had Office I

have managed to avoid having to complete timesheets. My new boss does not seem bothered as long as she can contact me and the work gets done. This si all notwithstanding my Parkinsons. I am very lucky., I would have to move away from where I live in a small flat if I had to leave work. It would affect my family life as I have three adul daughters and four grandchildren

S3) Just prioritised my day. Things I needed to do in the morning such as Assessments, home visits etc then in the afternoon make phone calls, meet families, liaise with social workers etc ,

S4) : I'm contemplating returning to my own business of consulting which i had prior to diagnosis. i feel this will give me more control over the level of work i will undertake and remove the employer power - but not the power of clients. if this becomes an issue - i will try to adapt the services/business to suit if possible. , No

S5) No, I have not made any changes of this sort yet. One problem with doing shorter hours that I am a bit concerned about relates to the Permanent Health Insurance scheme that my employer provides. Basically, this is an insurance policy that pays you a percentage of your salary, up until age 60, if you are unable to work. I am not clear what effect going part time would have, since my salary would reduce and future PHI benefits may therefore be reduced. It may be better (at least financially) to keep working full time, but be prepared to give up all together a little sooner.,

S6)No

S7) I got a disabled car parking pass., No

S8) Yes as stated earlier. Flexible working hrs and the option of working from home.,

S9)unanswered

S10) Automatic car

I now work from home on days I am not on the road this arrangement was to a large extent co-incidental however I am able to take advantage of the flexibility especially first thing in the morning when I haven't got any flexibility!,

S11) Not in the first year, then started a 4 day week., No immediaate family

S12) Not really, although we have cut back on my contribution to our tax deferred annuities.

S13) Yes I had to ask for ages to cut down my hours but I think they have finally got the message., My husband had to change jobs as he used to work nights

S14) No

S15) I have just returned to the new Autumn Term, two days down

I don't feel totally confident about my ability to do all I would wish to do.

The crux of the matter is that I have been trialling different levels of my medication and also an alternative to one but unfortunately nothing is sorted and somedays over the holiday period I have felt pretty down and dejected about the whole situation, I have three children and 1 grandson. My youngest is 17 and therefore, it probably wouldn't make a difference to them. However, it could interfere with my husbands ability to be flexible at work and to travel and work away from home for long periods which at present does improve our financial situation.

S16) I work from 8.30 to 1.00 anyway.,

S17) none, lots

S18) I tried to reduce my hours, but could not earn enough or find a part time job suitable.,

S19) , We had to purchase a property and took advice from an independent
financial advisor.

S20) : I resigned from the partnership, beleieving that the situation
would become increasingly unpleasant. I worked from home, took a number of
clients with me and have made more money in each of the last 4 years than in
the 3 years of the partnership., NO

3e)Did/do you use any equipment or have adaptation made and how successful were these changes

S1)None

S2) Not yet. I cant think of anything that would be helpful. When
using a computer mouse becomes difficult, then I will need something

S3) not answered

S4) have tried to master voice typing software. this has not
proven all that successful because it requires so much time to train the
software - its not quite up to the technical and scientific language
required. i'm sure it will soon. the software capablity is doubling every 18
months-so i'm told.

S5)None as yet

S6) No

S7)Unanswered

S8) Yes through the job centre scheme(forgot the name!) I received
a voice amplifier system to enable me to be heard in lge groups. My job
involves some public speaking

S9)unanswered

S10) Modification to indicators on car is very useful

S11)None

S12)Unanswered

S13) Not really just given a chair instead of having to stand for 5 hours.

S14)None available

S15) Not really - no special equipment, I do tasks at a time appropriate to how I am. i.e. It's not ideal to
take the coffee out to a teacher on playground duty when I know I am having a bad patch, or trying to put
tights/socks on a child after PE

S16)As above

S17)None

S18) I do not have any.

S19)Unanswered

S20) I drive an automatic car - for how long this will last, I
don';t know but it keeps me very mobile and lest me carry lots of gear
around. I've tried voice recognition software but I have not been impressed.

4)Leaving or staying

4a)What factors contributed to your decision to leave or remain in your job?

S1) My inability to function and to carry out more than 15% of my
normal workload. Mounting stress and a realisation of my limitations.

S2) The flexibility already in place.
The money and pension. My consultant thinks I can work till 65 which was
instrumental on my decidng to remortgage and build a garden room with
downstairs bathroom attached. This has improved my quality of life immensely
now and will enble me to stay in my home as long as possible

S3) I love my job. I wouldn't like to give something up that gives me
so much job satisfaction.

S4) As above

S5) Financial need - I earn a good salary and we have a lifestyle to
match, which may change dramatically if I finish work.
Also, I would need to have plenty to do to keep me active. I lead a busy
life. If and when I finish work, that may be a problem.

S6) Fortunately we were not dependant upon my wage.
I wanted to have some quality time at home before the disease progressed.
Work was very stressfull which wasn't good for my condition.
I was tired !!

S7) I wanted to work and got the support I neede.

S8) Staying because like anyone I need the money . I also want to
develop my career . Having Parkinsons doesnt change your aspirations or
needs.

S9) my kids were very yiung and i was getting tired frequently

S10) My condition at present is fairly mild and particularly as I live alone I feel that working keeps my
brain going

S11) Concentrating on computer tasks produced a certain stress which activated a 'bladder full' signal causing numerous trips to the loo. I was also experiencing greater 'on-off' fluctuations as the Sinemet wore off making me feel unable to guarantee I could open up on time.

S12) First and foremost, I was very confident that I would be able to get a disability retirement from the California State Teachers Retirement system. Secondly, I really was unable to teach to the standards I had set for myself. Finally, I thought that if the money aspect was under control, then I would rather spend the energy I had with my own children instead of coming home and falling into the couch, completely exhausted.

S13) I want to keep active and socializing

S14) Company couldn't offer alternatives.

S15) I like my job. My G.P. advises me to carry on as it is a therapy in itself. I like the people I work with and although I struggle to accept not being able to do things in the whirlwind fashion I used to, I am entitled to work if it is possible and in one or two instances, me at below par is sometimes better than one or two others on full steam!

I have just started going abroad for holidays and the pay check comes in handy for that too!

S16)Financial

S17) Parkinsons symptoms worsened

S18) Needed to work to survive

S19) : Contributing factors were the stress involved; my working was not essential.

S20) I needed to keep working to pay the mortgage, get my kids through school and to avoid becoming terminally bored.

4b)What was your employers reaction

S1)Suppportative, an interview was arranged by my Manager, with my Welfare officer , line Manager and myself to discuss retirement.

S2) Not relevant

S3) Supportive

S4) Unanswered

S5) Supportive/sympathetic, but it is too early to say if this
reaction will follow through into actions

S6) Sorry to see me go. I was told on the day I left that they would
find another job in the practice if I wanted to stay....too late buddy.!

S7) They did not want to lose me.

S8) One of my managers saw me as a competitor to his role . His
reaction was to 'encourage' me to work from home permanantly. This was a
little premature and a little too forceful.
Subsequently, I have applied for and gained a new post ...a higher grade
too! My employers were very helpful in the interview process. They were
great and I have gained a massive amount of confidence through this.
Parkinsons has not removed my skills at work ! I have continued flexable working.

S9) they were sad toknow about my sickness

S10) Excellent as long as i keep them aware of any changes

S11) Very sympathetic and left me to make the decision

S12) They totally understood and agreed with my decision.

S13) not much really, even now they complain if I say I may be in late because of an appointment

S14) Sorry to see me go and lose 32years experience

S15) My present Headteacher is very kind. He does not probe and lets me tell him things when
appropriate. I have only very recently felt the need to say anything at all. I felt very much that I was
letting myself and him down at the end of term because I couldn't cope with the way my body was letting
me down.

S16) Supportive

S17) sorry to see me leave

S18) My present employer re-employed me after I moved away when my husbands job was relocated

S19)Unanswered

S20) They expected me to fail - but I had been thinking ofd breaking up
anyway because each of us wanted to do very different things.

4c)How did you feel about leaving?

S1) Initially, fearful, mostly about the unknown future, finances etc.

S2) Unanswered

S3)Unanswered

S4) Haven't decided yet - will have mixed feelings - but i will get by
- i always have.

S5)N/A

S6) Both sad and happy.
leaving friends who had become good friends.
Thankful to say goodbye to the stress.
Maybe my garden would get some attention now.

S7)Unanswered

S8)Unanswered

S9)unanswered

S10)unanswered

S11) Disappointed in as much as I enjoyed the camaraderie of the office and of the clients.

S12) Torn because I loved my work and much of my identity was tied up in my career. On the other hand
I knew that I could be a better father and husband if I retired.

S13)Unanswered

S14) Very very Sad.

S15) I have toyed with the idea of going part time. I am not entirely happy with this option as, because I have been at the school for 7 years now, and have some responsibilities I know I would find it difficult to relinquish some of the control that I have at present.

S16)Unanswered

S17) gutted

S18)Unanswered

S19) Sorry because I had loved the job but glad because I was able to come to terms with the diagnosis of PD.

S20) : I should have done it earlier! I'm very happy that I retained control over events - and that I have more clients than ever

5)Rights and finances

5a)What was/is your knowledge of you employment rights

S1) Quite extensive I had been giving advice to young people and adults on training and employment opions or over 15 years

S2) I have good knowledge of my employment rights. However, if I become morre incapacitated, I think I will find it difficult to 'work the system.

S3) I have PDS employment information

S4) In the private sector - if i can't do the work as required - i have to reduce my workload/type and hence pay or possibly cease all together. the australian act is quite clear on this. Finally, if i could not drive - i couldn't work for an employer in my current profession.

S5) I have some knowledge, based on guidance from the Parkinson's
Disease Society

S6)Basic

S7) Only that they can't sack you for having PD.

S8) Enhanced through attending PDS awareness day in Manchester.Also
through internet use Disability Discrimination Site

S9)unanswered

S10) Little except to say that I was aware that they should not discriminate against me

S11) Reasonable

S12) I think I have a pretty good grasp of my rights. In order to fire me the district would have shown
over a period of time that I couldn't do my job. They would have needed to adjust my working situation
as it became necessary.

S13) I KNOW A BIT AS i SENT FOR EMPLOYMENT PACK.

S14)None

S15) I knew somehow that Employers are obliged to employ a certain percent of 'disabled' staff however
broadly the term is defined. I also know that unless I do something drastically wrong there would no real
grounds for requiring a resignation from me. I would offer my resignation if I felt that there was the
slightest way I was not fulfilling my role properly at school.

S16)Unanswered

S17) quite good

S18)very little

S19)Non existent
S20) None - but I got a lawyer who knew lots about the law of
partnerships.

5b)Did your employer have any knowledge of the disability discrimination act

S1) Yes fuly aware of and complied with the act.

S2) Yes but they need promting now and again!

S3)Oh yes

S4) Don't know.

S5)Not answered

S6)Probably

S7)yes

S8) My employer will have it somewhere.

S9)unanswered

S10) At HR level certainly

S11) Basic knowledge

S12) Yes, since I was in special education we worked with these types of laws on a regular basis.

S13)I don't think so

S14)Yes

S15) I imagine he does, he is young, caring and upholds the 'Investing in People' policy.

The underpinning of all that he does, his predecessor and myself is that we are all praticing Christians - and it makes a difference.

S16)Unanswered

S17)yes

S18)Unanswered

S19)Yes

S20)No

5c)Which if any benefits have you claimed

S1) Incapacity benefit as all that I was entitlen to according to my interview with the DHSS. I was in receipt of DLA.

S2) I have tried to claim DLA care and failed

S3)Not applicable

S4)Unanswered

S5)None

S6)DLA, Incapacity Benefit

S7) Blue badge car parking pass

S8)Disability Living Allowance

S9)social welfare

S10)none

S11)none

S12) I took a disability retirement. In addition, prior to my diagnosis I bought a salary protection policy from UNUM Provident which has provided 25% of my preretirement salary for two years tax free since my employer didn't contribute to the policy.

S13) mobility and working persons tax credit just since last year.

S14) DLA, Incap & Carers

S15) I am presently awaiting the results of the DLA claim.

S16)Unanswered

S17) DLA, incapacity benefit

S18) I attempted to claim DLA. I still pay for my prescriptions and dental and eyecare

S19) I claimed Incapacity Benefit and then Disability Living Allowance.

S20)DLA

5d)When you left work what was your financial situation (what source did your income come from)?

S1)Prior to leaving I made extensive enquiries into what I would be
entitled to. In practice though what I received and what I was told I would
receive were different. My pension was added to my incapacity and taxed.

S2)Unanswered

S3)Unanswered

S4) I have income insurance to 65 years. But i expect a fight with an
insurance company as i expect them to look for every possible way to avoid
payment or reduce the payment. this is speculation at present. it would
amount to a substantial amount over 15 years.

S5) unanswered

S6) ok. could live with just my husbands salary.

S7)Unanswered

S8)Not applicable

S9)unanswered

S10)unanswered

S11) Being over 65 I was receiving state and small private pensions but the loss of the regular income has
meant planning for a restricted future.

S12) My wife and I both work as teachers.

S13)Unanswered

S14) Company Pension and savings

S15) Can't answer this but pressume I would not get any income

S16)Unanswered

S17) Redundancy pay, mortgage protection insurance, TGWU driver care loss of license insurance

S18)Unanswered

S19) When I left work, I was dependent on my savings and my husband's income.

S20) Self employed. I took a big tax hit in year 1 but apart from that I'm better off.

5e)Were you better/worse off financially?

S1)Finances: I dropped £600 per month on retiring. one benefit (Reduced Earnings Allowance) which I had been receiving since 1982 was stopped. The reason given was my retirement og ill health grounds had to be due to the orginal injury that led to the benefit. This was a loss of almost £200 pm. I have other disabilities one related to PD and one unrelated preventing me from working normal hours.

S2) I would be infinately worse off if I left work. My pension is very small due to an unfavourable divorce settlement and not starting work till I was forty. I imagine this affects many women with disabilities.

S3)Unanswered

S4) : if paid the due amount - similar.

S5)Unanswered

S6) slightly worse

S7)Unanswered

S8)Unanswered

S9)better before my sickness

S10)unanswered

S11) : Although I had been doing the job for 15 years, I was technically self employed but had been planning for the reduction in income.

S12) believe it or not, since there are no longer so many deductions being taken out of my check, my net pay is the same!

S13)Unanswered

S14)No!!

S15) I would be worse off.

S16)Unanswered

S17) I dropped from £35,000 a year to £5,000 a year

S18)Unanswered

S19)I was worse off

S20)Unanswered

5f)Did you or your family have to make any changes because of this?

S1)No answer

S2) Yes

S3)Unanswered

S4)Unanswered

S5)Unanswered

S6) no

S7)Unanswered

S8)Unanswered

S9)unansered

S10)unanswered

S11)Unanswered

S12)Unanswered

S13)Unanswered

S14)Unanswered

S15)Unanswered

S16)Unanswered

S17)Unanswered

S18)Unanswered

S19)Unanswered

S20)Unanswered

6)Moving on

6a)Have you experienced applying for jobs since your diagnosis?

S1)I recently applied to ability net for a post advertised in Parkinson's mag

S2)Yes

S3)Unanswered

S4)No

S5) I saw a job that I thought sounded a good opportunity for a
step up the career ladder. I was concerned that Iwould put myself under
additional stress and that would worsen my symptoms, so after consideration,
I did not apply. I would be obliged to tell any potential employer about my
PD and I feel as if this would count against me in their selection process.
As a result I feel as if I need to stay with my current employer.

S6)no

S7) Yes, internally within the civil service.

S8) Since diagnosis I have wanted to apply but held back because I
experience extreme nerves which I didnt previous to diagnosis.
However I did apply and was treated very well . I gained the position and
promotion.

S9)no

S10)no

S11) Not yet but intend to in future.

S12) I have a videography business and I have bid on several projects/

S13)Unanswered

S14)Unanswered

S15)No

S16)Unanswered

S17) I went to see the Disability Employment Adviser at my local job centre, she told me of a scheme that
Transco the gas pipeline firm were actively seeking to help disabled people to work for them. I attended a

open day in Newcastle in August to find more about the scheme, there were 30 other people up for selection but I managed to get selected to go on the training course consisting of 3 weeks training by Finchale College in Durham to get my skills a little bit more up to speed, I'm 2 weeks into this course and I sure can type a bit faster than before.

S18)Yes

S19)No

S20) : I regularly make bids for contracts, make presentations etc.

6b)Have/did you select particular posts because of your Parkinson's (i.e. part-time)?

S1)n/a

S2) I have looked for things I can do to subsidise my current employment with the intention of reducing those hours. Board membership; that sort of thing.

S3)Unanswered

S4)Unanswered

S5)Unanswered

S6)Unanswered

S7)no

S8) No its full time.

S9)no

S10)unanswered

S11)unanswered

S12) I don't do weddings since they are a "one shot" situation, and I would hate to miss a one of a kind moment due to me being "off."

S13)Unanswered

S14)Unanswered

S15)Unanswered

S16)Unanswered

S17) no driving involved

S18)Unanswered

S19)Unanswered

S20) I travel less but I work 50-60 hour per week.

6c)What have been potential employer's reactions to your condition?

S1)Reactions: N/a

S2) Can't really say. Some have been good with sending applicatoin forms that can be completed electronially.

S3)Unanswered

S4)Unanswered

S5)Unanswered

S6)Not applicable

S7) They thanked me for being honest. Told me it was a busy post (which they told everyone.

S8) excellent. They spoke to me prior to the interview to asses my requirements. Candidates WERE to be given a presentation on the day to deliver. FOLLOWING discussion about slowness and size of handwritinh this was CHANGED. ALL candidates were given the topic in ADVANCE

S9)not applicable

S10)unanswered

S11)unanswered

S12) Hasn't been a problem as of yet, but my meds control my symptoms to a great extent.

S13)Unanswered

S14)Unanswered

S15)Unanswered

S16)Unanswered

S17)Excellent

S18)Unanswered

S19)Unanswered

S20) No problsm that I know of so far, though PD may have been a
factor in not winning some contract

7)Work /life balance
7a)What impact did maintaining or leaving your employment have on your leisure activities or family life and how did you address those issues?

S1) Made me feel a lesser person, affecting my self esteem. Prior to
retiring I got involved in a voluntary capacity with PD, my involvement
continues.

S2) : I would be unable to afford leisure activities or to buy things for
my garden; a crucial part of my survival both physically and mentally!

S3) Am very tired at weekends,and feel unable to help look after my
very boistrous 4 year old grandson. Also housework slides. I have someone
who does my ironing for me.

S4)Unanswered

S5) I feel a lot more tired when I get home from work in the evenings than I used to and this has reduced the things I do outside work.

S6) Difficult to just be housewife again. Needed to boost my own moral, felt a little useless. Not needed, had to find identity again.
I don't go out in the evening as much now, but that's my preference.

S7) Not applicable

S8) Massive impact. I just cant do what I used to I no longer have the physical energy to go to exercise classes after work or the Gym.
I found that work took all my stamina with nothing left for the family. Therefore, I have increased my medication to give me a boost in the evening so my family dont just see the 'dregs'!
My husband is going to help me take over part of the garage to enable me to exercise at home. WE are starting to take long evening walks.
We dont socialise much but I'm not on top of time?
this yet!

S9) Unanswered

S10) I move slightly slower otherwise I have maintained previous hobbies although choreographer for music society is a bit tricky!

S11) Just cut down on my spontaneous events as I now need a little more pre-planning.

S12) I'm coming to grips with this right now. I am having to redefine myself. My kids really like having an at home parent and I'm beginning to do some of the things I aalways wanted to do but couldn't. I'm reading an excellent book right now about this very subject called

S13) I am worn out by 9.30 at night and I do not go out very much at night. My husband has to do a lot more in the house than before.

S14) Unanswered

S15) If I left it would curtail certain freedom with leisure activities such as an annual holiday, spending money on the garden which I love. Not spoiling the grandson, or indeed helping the children out generally.

S16)Unanswered

S17) I worked such long hours as a HGV driver I didn't have a lot of spare time for fun now i've got loads of time but no money

S18)Unanswered

S19) : I was now at home 24 hours a day and once the medication settled down I was desperate to keep my brain active. I joined the Bexley University of the Third Age in June 1996 where I taught Beginners German, learnt Italian, joined a Quiz Group; Geology Class; Gilbert & Sullivan group. I also joined the Committee and was Publicity Officer, Membership Secretary and Newslette Editor. In 1997 I joined the local PD Branch as Hon. Secretary

S20) : I work harder than ever, but I'm based at home and I see a lot of my children.

7b)If you have left work, what do you do with your time?

S1)Light gardening Help produce a Parkinson's paper for N.I.

S2) I would garden and sit looking at the garden. Also see grandchildren

S3)Unanswered

S4)Unanswered

S5)Unanswered

S6) Life is like one big holiday. I can do what I want when I want as long as my medication allows.
I have a new grand-daughter and spend as much time as possible with her.
I work in my garden

S7)Unanswered

S8)Unanswered

S9) draw picture and sew cloths forkids

S10) That's why I haven't left

S11) It's only been 2 months so am just gettng use to it. I do some gardening for elderly neighbours; have been assisting the PD branch secretary on various endeavours and am archiving my photgraphic collection. And the new football season has started with maatches to attend.

S12) I try to exercise daily, either at a health club or in the neighborhood. I read and go to the library. I take care of the house and the grocery shopping. I garden. I make movies for nonprofits. I golf once iin a while (badly.) I love to travel and really want to start doing that again. i watch my kids play sports.

S13)Unanswered

S14)Unanswered

S15)Unanswered

S16)Unanswered

S17) fitting the kitchen we bourght before I left work i'ts goig a bit slow as I keep dropping the screws

S18)Unanswered

S19)See above

S20) Go mad.

8)Looking back

8a)Retrospectively, is there anything that you think you should or could have done?

S1) not really.

S2)Unanswered

S3)Unanswered

S4)Unanswered

S5) It's easrly days yet, so I cannot say how successfully I
have handled the issues.

S6)No

S7) Gone back to the doctor earlier. It took too long to be
diagnosed. If the podiatrist had been more honest, it would have saved a
lot of worry and heartbreak.

S8) No Im quite pleased

S9)Unanswered

S10)unanswered

S11) Not really. Perhaps I should have made greater contributions to my pension, but that would be the
case even without the PD.

S12) No, not that I can think of at this point.

Decisions: Right now I guess the only thing I'd change is that I wish I had spent more time pursueing
hobbies while I was younger.

S13) May be tried to explain more how PD affects me.

S14)Unanswered

S15)Unanswered

S16)Unanswered

S17) I should have gone on the sick before I was made redundant and I probable would have got my
pension as if I had worked till I was 62

S18) Perhaps taken a college course so that I could diversify

S19)No

S20) Probably not-apart from negotiating an even tougher deal
when I left.

8b)Do you think you made the right decisions – would you change anything if you could?

S1) I made all my decisions based on information available to me at
the time. If ii could go back it would be to get a more accurate prognosis
of my financial state.

S2) I think I have made the right decision to go on working as long
as I can. I have started a list of things I could do if I had to leave, both
paid and unpaid. It will be vital to keep some sort of routine. Not least in
order to remember what day it is!
I do't get out as muc as I did, a smy engery goes into work. I am aware I
need to keep up out of work contacts or there will be a sense of loss if &
when I do give up work. I belong to a pressure group that lobbies for better
access for the disabled.

S3)No

S4)So far not yet

S5)so far so good

S6)Yes – no change

S7)As abovve

S8) Yes especially remaining in work

S9) no i am notsure

S10)yes

S11) Yes. I could only do it differently if there were some new and more effective medication developed.

S12)No answer

S13) Yes I should try to be more forthright about my needs

S14)Yes

S15)Unanswered

S16)Unanswered

S17) what will be will be or so they say

S18) Yes, but I would like to take up a sport again, I used to play squash, but have not found an alternative yet.

S19) yes and no

S20)yes

9)Advice

9a)What tips would you give to someone who has recently been diagnosed regarding managing their employment?

S1)Don't let the stress of trying to remain in employment affect your employmeny. Take some time off work if you think it is needed to get advice, rest and things sorted out in your own mind.

S2) Get someone on your side. Compare note and tips. Join an active pressure group. This will reaffirm that you are not a nuisance but have rights like eveyone else and deserve to be treated with dignity.
Write a briefing note so that people are informed about Parkinson's and how it affects you. Drop it into the conversation. If people fill you teacup too high. Say 'I'll just have to tip a bit out of this; nothing personal' rather than trying to carry it. Tell them what you can do as well as what you can't do. 'Don't ask me to make sandwiches, but I can put the chairs out and keep so-and so out of your way by chatting'.
Join a trustee board where you can learn about disability rights. The Citizens Advice Bureau is perfect. They have courses. You can use your experience to advise them.

S3) Be as honest as you can be. Trust your instincts, you' ll know if the time is right to tell.

S4) Work as hard as you can for as long as you can to keep your mind
active and avoid depression - try to lead as active and normal a life as
possible - even if you are fincially sound!

S5) When you first tell your employer about your PD, tell them what PD is
and explain that its progress is different for each person. That will mean
that no-one can say how much effect there will be in the future on your
ability to do your job and what the time scales will be. I suggested an
arrangement for periodic reviews - say every 3 or 6 months - to have a
meeting to give you a chance to tell them how you are being affected and to
ask for specific support with aspects of your job. It will also give the
employer chance to tell you how they feel your job is being affected, so
that you can work together to find the best courses of action going forward.
Most of all, keep a positive attitude.

S6) Stay as long aas you want or need to.
Ask your employer what they can do for you.
Research all aspects of employment rights.
Check out your pension.. Mine doubled if I had contributed for 5 years and
left through ill health !

S7) Don't give in, but know your body. Rest when you need to.

S8) Gain an insight of your condition through reading, the helpline etc to
give you confidence. DONT give up work as once you master your symptoms you
realise that YOUR SKILLS AND ABILITIES REMAIN!Parkinsons just makes them
differently delivered! Claim Disability Benefits attend Welfare Rights
Training Days run by PDS

S9) forget about carrer and take care of your helth

u are most importwnt tou

S10) Don't overeact or rush into anything

What may appear as a life changing diagnosis need not change your way of life in any percebtible way

S11) Try to relax. Anxiety can be a real problem and should be avoided if at all posssible.

S12) If at all possible be honest with people about you PD issues. Having the disease is stressful enough
without compounding things by keeping it secret and trying to move/act "normal." You have a new
"normal" and that's okay! Plus youo just never know who might have a great idea or contact for you.

S13) Tell them as much as they can about PD

S14)Call the helpline now!!

S15)Unanswered

S16)Unanswered

S17) If you have a works pention that will pay you if you can't work then grab it

S18) Work for as long as you can. Unless it is very apparent, then I would not tell them. Make sure you tell a close friend, just in case you have a problem. Never look for sympathy, always try and carry on as normal. Its not always easy, but people respect you for it.

S19) Do not put yourself under any stress whatsoever. Follow your
instincts and do not be persuaded by any body else - only you know how you
feel.

S20) Be absolutely rational and cold-blooded about assessing your position.
Think several moves ahead, Exert control.

Appendix M Contact Summary Sheets

[*date and location of Focus Group 1*]

Took place in the home of the group organiser – very small living room, but this helped to create an intimate atmosphere, and I don't believe anyone felt uncomfortable.

4 people with PD (all male) and their spouses. 2 in work and 2 retired ranging from mid 40s to mid 60s.

Very articulate speakers all comfortable with each other, spouses also willing to contribute but left the main speaking to their partners. Main themes coming out regarding work was:

How to leave work with the maximum benefits – on what basis do you leave, how can you find out what you are entitled to

How to stay in work with the maximum support – who provides it, where can you find out about it?

Particularly for younger people it is important to retain the finances they were/are on at work, due to family commitments.

Also want to know if they can work part-time after retiring or go into a different job, again does it affect benefits? Feel they can still contribute to society but don't know how to go about getting a 'new' job.

This group felt that leisure was less of a priority due to reduced finances. However felt that it was extremely important to maintain social networks and outlets. Spouses contributed particularly in this discussion. Regarding sports activities, most used 'get fit' subsidised schemes and appreciated them and didn't feel any stigma associated with using them.

[date and location of Focus Group 2]

Intend to focus more on what people need from the web-site this time. And on strategies.

Location – in a large assembly room building in the centre of Sheffield. Large modern and warm room, no-one there when I arrived, set up recording equipment and waited. Some people arrived (one elderly (72) lady and her husband) and then some others, it was 30 mins before the organiser arrived. Handed out information sheets and consent forms. All agreed to participate. Feeling that everyone was anxious to start their party as soon as possible. Elderly lady just wanted to talk about her diagnosis and drugs – very irrelevant and most of the group realised that. I should have been more assertive, but didn't want to be rude and she didn't draw breath!

Main respondents consisted of the organiser, another single lady, a couple (woman with PD), a lady who came alone but had a family, and another couple (man with PD), plus the elderly couple, plus others who wandered in later. Three people had left work 'badly' one had a good experience and one man was still self employed. One woman had taken up part-time work from home and another was really trying to get a job but with little success, so a good range of experiences. However, other people started to arrive and sit at the back so after two attempts to try and include people, just gave up and concentrated on the main respondents. One guy, who obviously feels he has a lead role in the group kept interrupting with very irrelevant and very long comments and questions. The rest of the group were rolling their eyes when he started to speak and again I feel I should have been more assertive, but didn't want to be too harsh as to break the atmosphere of the group.

Had less time than the last group and really felt pressurised into finishing.

Tried to examine more about getting another job once you have left due to Parkinson's and also more about how useful the website would be.

Most useful ideas:

Need advice for employers, what to expect, what they can do etc.

Also need advice for potential employers – i.e. one of the respondents has said that PD affects her performance at interview – facial expression, voice tone

- Group lasted around 1 hour

[*date and location of Focus Group 3*]

18 attendees ages ranging from early 40s to 60s.

good venue for recording although large size of group gave some concerns to ensure that everyone was recorded. Also didn't have the connector for the pzm mic, however the video recorder has picked up everything.

The large group meant that subjects took much longer to discuss and the time flew – group lasted around 1 hour 10 mins.

Good mix of retired and those still working.

Suggestions – employers guide for what to expect (whilst people are still working) and guide for potential employers.

One respondent mentioned that the employment case studies were very useful Still people uncertain about 'how' to leave work in terms of benefits i.e. retire, pensions or benefits.

Some people gave examples of using technology to help, cutting hours etc. But most said that flexibility was required by employers in terms of starting times, breaks, places to rest etc. Possibly getting monthly hours would help, having a space to take a nap. Some people spoke positively about how Parkinson's had affected their employment – one man had to get to grips with new technology to help himself, another had to be a better self manager and leave work on time and not start too early and delegate responsibility, one said it made her colleagues really support her. Some people spoke of employment as being the best medicine – certainly in the earlier stages. Again the difficulty of giving up a job you can't do and finding one you can do was raised. Some people still want to contribute, but either can't under the terms of their employment or have difficulty getting employed.
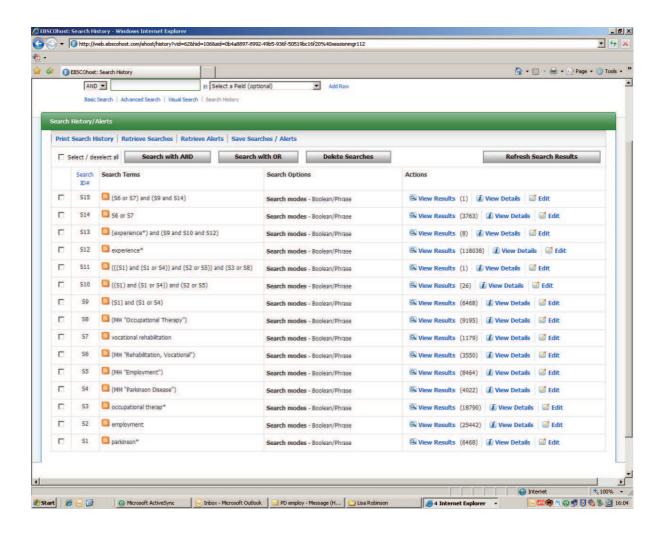

Initial thoughts following the focus groups

It is obvious that employment issues are high on the agenda for these people. More so than leisure. There is a huge need for support and information regarding the decisions they have to make in relation to employment. Need to ensure that it is not a decision that they regret either financially or mentally.

Leisure issues seem to relate to filling in the time once retired or locally based in terms of local leisure centres etc. Perhaps need to make the site more 'tools' for managing employment i.e. case studies, employers guide etc.

Need to contact society re. Case-studies booklet and relate more to financial outcomes.

Appendix N - Example of search history

Appendix O 'Parkinson's and You' website

Home page

This site has been developed for younger people with Parkinson's to help them with any difficulties they may be having relating to employment, and provide advice and suggestions from others in a similar situation. The site is not an extensive guide to employment but aims to allow visitors to the site to share others' experiences. Younger people have reported a lack of support and information regarding employment issues. This site aims to assist people with Parkinson's to consider the options available and help them to make the right decision for their circumstances.

This site is the outcome of a research project funded by a grant from the Parkinson's Disease Society. It has been carried out by Angela Birleson, an occupational therapist who has experience of working with people with Parkinson's, and experience of carrying out research projects. A steering group comprising of younger people with Parkinson's from the North East of England has guided its development.

Information regarding the employment experience of younger people with Parkinson's was gathered using a nationwide questionnaire, and a series of focus groups. This information was then used to inform the structure and content of the site. An initial version of the site was launched in August 2004 and additional contributions from visitors to the site were requested. These contributions were collated, and the site which you are visiting today was launched in October 2004. It will be evaluated again in December 2004. The initial site received contributions from the USA –we welcome our overseas visitors! The final site however focuses on the situation in the UK.

Thank-you to everyone who contributed to the development of this site – we all hope it will be useful to people with Parkinson's who are currently considering their options regarding employment.

If you have any comments either positive or negative, please click on and fill in the form in the Evaluation section.

Please remember that any information or advice given in this section of the website is purely reflective of the experiences and opinions of individual contributors. Opinions expressed here do not necessarily reflect the views of any official organisation.

Your experiences

The comments and accounts gathered have been broken down into the headings below. The headings represent the important themes or topics that people with Parkinson's identified in relation to their employment. Click on the headings to read about the experiences of other people with Parkinson's.

Impact on employment

Disclosing your diagnosis

Support and assistance

Leaving or staying

Rights and finances

Moving on

Work/life balance

Looking back

Helpful tips

Impact on employment

A common worry for people diagnosed with Parkinson's is 'How will it affect my work?' Obviously it depends on the type of job you have! But almost certainly you will notice changes (you can see how other people have managed those changes in other parts of the site). The list below represents some of the effects that people with Parkinson's have noticed on their ability to carry out their job, particularly in the early stages of the condition. Not everyone will experience all or indeed any of these.

Fatigue

- General slowness with moving, carrying out tasks, or feeling like you are 'getting under other people's feet'

- Loss of concentration - finding it hard to focus on things and complete them

- Memory loss

- Poor handwriting

- Difficulty with jobs that require fine finger movements or dexterity e.g. difficulty in using the keyboard, problems with filing or handling paper

- Difficulty in giving presentations

- Difficulty using one hand more than the other

- Feeling more prone to stress (and stress making other symptoms worse)

- Feeling very tired if driving for a long distance

- Getting very stiff if remaining in one position for a long period – either sitting or standing - and getting cramps in legs

- Difficulty with balance

- Feeling clumsy

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Disclosing Your Diagnosis

Disclosing your diagnosis is a very personal thing. People differ in the timing of disclosing their diagnosis to their employers and colleagues, and for a range of reasons. Below are some comments;

If your work involves driving or if your ability to do your job may compromise the safety of others then you must disclose your diagnosis. The DVLA and your motor insurance provider must be informed of your condition.

"I informed my employer immediately following diagnosis having sought advice from my Union who advised regarding insurance implications."

"I felt obliged to tell immediately, due to safety at work and I then had to undergo regular medicals."

"Due to the nature of my work I informed my employer as soon as I was diagnosed. I was then retired due to ill-health – I was only 19!"

"Your colleagues or employer may have noticed changes in you and have guessed there was 'something wrong'."

"My employer and colleagues had observed the difficulties I was having anyway, so as soon as I received my diagnosis I informed them. I would have felt awkward if I had informed my employer but not my colleagues."

"My employer and colleagues knew that there was something wrong so they supported me through the whole year it took me to get diagnosed."

"I felt my colleagues had a right to know."

Some people have commented how hard and stressful it is to cover up their symptoms if they haven't disclosed to their employers or colleagues.

"I disclosed to my team immediately so that they know why I am having a bad day!"

"I find it less stressful being honest and not having to cover up my symptoms."

"I didn't disclose for about a year but when I did my employer was very sensitive – and I didn't have to make excuses anymore when I was having a wobbly!"

"Not telling my colleagues made me feel socially isolated."

Your employer and colleagues may actually be an additional source of support for you.

"My employers and colleagues were brilliant and supportive - I had no reservations about telling them at all."

"The level of support from colleagues has been amazing."

"I disclosed after eighteen months, my employer changed my car to an automatic, and my colleagues were generally supportive."

You may want to give yourself time for the diagnosis to 'sink in' and for you to understand it yourself before telling anyone else.

"Five years on and I still haven't disclosed yet - I am just trying to ignore it"

"I took 8 months to disclose, I felt I had to understand more about it myself before I could explain it to other people."

Some people are worried that their diagnosis will be used against them.

"I had reservations about telling as despite the DDA giving protection, I knew that there were redundancies looming and thought my employer might get rid of me using another reason."

"I was worried that colleagues may resent giving extra help or support"

Most people felt that generally the response is better than you might imagine!

"The actual disclosure wasn't as bad as I thought it would be – I had been worrying myself sick over nothing!"

There have been mixed reactions to the disclosure from employers and colleagues.

"It is difficult telling people because their reactions are so different - it is hard to know what to expect and therefore I avoid telling people."

"Some colleagues felt embarrassed, they didn't know what it was, didn't want to ask."

"I informed my employer straight away and he immediately sat down and devised a plan of action to help me in my work."

Some people have said that when you disclose try to give as much information to your employer and colleagues about Parkinson's as you can (you can get some information leaflets from the Parkinson's Disease Society). You should then go on to describe how it might affect you in your day-to-day work or identify areas you are having difficulty with currently and let them know what support they can provide, for example:

"I would be grateful if one of you could carry my tray in the canteen."

"You might notice that my performance at work changes not only daily but during the course of the day."

"I might need to adjust my hours around the timing of my medication."

"I will be working flexible hours so I can take a longer lunch break to recharge my batteries."

Don't forget also to let them know about the areas that you are not having difficulty with and remind them that the social aspect of work is still important.

"I have twenty years experience in this line of work, I'm sure I can find a solution to most of my problems!"

"If I am unable to go out for a drink after work because I am tired one day, does not mean that I will always feel that way, please keep asking me!"

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Support and assistance

People with Parkinson's have said that equipping themselves with all the advice, support, and information they can get, makes them feel more confident. Below are some ideas that range from equipment, to fatigue management strategies.

Access to Work Scheme (see useful links) is enormously helpful; some people have said that it has enabled them to remain in employment for years longer. Support from this scheme has included funding for a support worker to do the tasks that a person with Parkinson's is unable to do, paying for equipment, or help with getting to and from work. Go and see a Disability Employment Adviser (DEA) at your local job centre – they are not just for helping people to find work, they can assist you to maintain your employment.

Being able to work flexible hours is a great help. Varying start and finish times, being able to 'borrow' and 'make up' times can enable you to work when you are feeling at your best. Organise your day so that you will be doing the difficult things when you are not fatigued or when your medication is working. Take regular rest periods – take a lunch break even if you have never taken one before!

If you are going through a bad patch, particularly if you are changing your medication, take some sick leave (if you are entitled to it) it can give you a chance to sort yourself out. Just because you have taken sick leave does not mean that you can never go back! Once your medication is sorted out you might feel able to take up your employment role again.

Setting up working from home facilities can mean that you eliminate the rush-hour drive, which can be draining. Often people find they can concentrate better at home with less distractions. Some employers might let you work from home for part of your working week. Getting a disabled parking badge can mean that you can park nearer the office, lessening your fatigue on arrival.

It is essential to set up regular meetings with HR/personnel and your manager, so that you can address issues as they arise and nip them in the bud, rather than letting things get out of control. Sometimes employers are rather vague about the support they can give, so you need to be able to ask for specific help. Being honest with your employer and colleagues about your capabilities enables you to access the support at work that you need.

Think about changing roles within the organisation if you are having difficulty with your current one. You may be able to delegate the tasks you find difficult to do to someone else, in exchange for doing some of their work that you find easy.

It is great if your colleagues are supportive - even just emotionally, but this can only happen if you share what you are experiencing with them.

If you spend a lot of time at a desk, get assessed for an ergonomic desk and chair to help minimise stiffness.

 If you operate a keyboard, some people have found voice-activated software for typing useful, (others have given it a mixed response, but technology is improving all the time!)

Some people find an automatic car useful if they are driving a lot. You can get the controls (indicators etc) modified if you are having difficulties with one of your hands. Use public transport instead of driving, especially for long journeys.

If you feel that you would like to change jobs completely, the DEA can help you get ready for another job, perhaps taking a college course, or arranging work placements.

Outside of work, your PDNS, consultant, GP, Occupational Health adviser, and occupational therapist have also been found to be great sources of support and information regarding maintaining employment. Also other people with Parkinson's are a great source of help!

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Leaving or staying

Whether you remain in employment, leave or move on to another job is a complex and personal decision. Below are some of the reasons people with Parkinson's have given for remaining in or leaving work:

These are some of the reasons people have given for their decision to stay at work:

"I need to work to survive financially."

"I am fearful about leaving work in terms of my financial future."

"Flexibility at work has enabled me to stay."

"My consultant has given me positive messages about working."

"My GP has advised me to carry on as long as possible – I view it as therapy!"

"I have job satisfaction and I enjoy my job."

"I want to work!"

"Working gives me a routine and helps me time my medication. Also it is exercise that I wouldn't get if I was sitting at home."

"I want to keep mentally and physically active."

"I would miss the camaraderie and social contacts that work brings."

"I am not going to leave until I can't drive anymore."

"I am worried about becoming bored when I finish work - I like to be active!"

These are some of the reasons people have given for their decision to leave work;

"My husband and I are not financially dependent on my wage."

"I wanted to have quality time outside work before the disease progressed."

"I wanted to be a better parent instead of just coming in and falling asleep."

"Stress at work was worsening my symptoms." "I was just too tired."

"I felt that I wasn't getting through enough of the workload."

"I realised my limitations."

"I was experiencing greater on/off fluctuations – I couldn't predict my performance."

"I was confident I would have enough money from pension and benefits to survive."

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Rights and finances

Knowing your rights as an employee can be a minefield – it is by no means simple and straightforward! You need to equip yourself with a good working knowledge of the system and stand up for your rights at a time when you perhaps don't feel that you're most clear headed or assertive! Below are some things to think about that have been highlighted by people with Parkinson's who have found themselves in that situation:

People with Parkinson's have said that it is important that you take control of the situation and don't leave it to anyone else to look after your interests – fighting talk!

Employers need prompting about the Disability Discrimination Act (see useful links) so you need to have personal knowledge. Larger organisations seem to be aware of the DDA but often you need to be giving prompts at a more local level i.e. to your line manager.

Undoubtedly for the majority of people their financial situation is worse when they leave work. It is important to make sure that you claim everything that you are entitled to, and get a clear picture about how much you will receive, before you make the final decision to either reduce your hours or leave, taking into consideration things like taxable income, pensions, benefits etc. If you feel that working part-time would be a better option for you (even within the same job), contact the Disability Employment Adviser at your local job centre to see what options he/she might be able to come up with.

Check and double-check your pension entitlement before leaving work with your pension provider. Will leaving work early affect it? Check out pension arrangements both in terms of   reduced contributions (if you go part-time) and means testing in relation to benefits if you leave work. Check it out from a few different sources, as some people have received inaccurate information.

Make sure that you are leaving on the most favourable financial terms for you – early retirement, retirement on the grounds of ill-health, or some people have even been offered redundancy packages - check out all the options.

Don't be embarrassed about claiming benefits - you are entitled to them! Keep trying to claim benefits, just because you have been knocked back once, doesn't mean that you can't try again! People have had mixed success in trying to claim Disability Living Allowance (see useful links) which is a benefit you can get even when you are still in work. Another benefit that people have mentioned is Incapacity Benefit (see useful links).

The Parkinson's Disease Society have some extremely useful fact sheets regarding employment and benefits (see useful links and contacts) and you can contact their

advisory services to speak to someone. Community Support Workers employed by the PDS can visit you at home and can even help you to fill in the forms! They can be contacted through your local Community Service Manager.

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Moving on

Your career doesn't suddenly stop just because you have Parkinson's. Applying for positions either within your place of employment or for a different employer is part of most people's career development. However, having Parkinson's is something that should be taken into account when you are applying for jobs. Below are some issues that have been highlighted by people with Parkinson's:

Some people have mentioned not wanting to apply for a promotion as they do not want the additional stress of a higher position, as they feel this might worsen their symptoms. Other people have stated that they feel more urgency to progress 'up the ladder' as they want a higher salary to help sustain them if they want to give up work, and also in relation to a 'final salary' pension.

Just because you are applying for a part-time rather than a full-time job does not necessarily mean that you want a less challenging or more menial job! Think about job share options at a level of seniority that you feel is appropriate to your ability and experience.

Just because you have left one job does not mean that you may never work again! Thinking flexibly about other employment options has led some people to become self-employed or to set up their own business, so that they can control their own workload and hours. Some people have looked for part-time consultancy or memberships of boards so that they can give up their major job but still have an income.

The Disability Employment Adviser at your job centre can be very helpful, and may recommend a college course or training to get you into a new line of work. Some people have reported that their DEA has helped them to access a variety of great schemes that they would never have discovered without their help.

Ask for electronic versions of application forms if you have difficulty with handwriting.

Although some people feel as if disclosing their diagnosis to potential employers would count against them, always be honest when completing any questions about your health or disability, as this may form part of your contract if you are employed.

When going for an interview, time your medication appropriately or ask for a specific interview appointment during the part of the day when you will feel at your best. Inform the interview panel either before the interview or when applying the symptoms you display, and how they might affect your performance in an interview (see employer's guide).

If you do leave your paid employment, think about using your experience in voluntary or community work. Often you can do as much as you feel able to do, and it is a great way of keeping active and meeting people.

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Work/life balance

Much is heard about maintaining a work/life balance, but when you have Parkinson's this suddenly becomes a work/life/Parkinson's balance! Below are some issues that have arisen for people with Parkinson's when considering their work/life balance:

Many people with Parkinson's who are in employment have mentioned the fatigue they experience.

"On a weekend I just want to sleep."

"When I get in from work I can't be bothered to do anything – I just fall asleep in front of the TV."

Obviously something has to 'give' and this is when thought has to given to your priorities in life. It would be simple to say give up work and spend more time with your family or on leisure activities but the decision can be more complex than that.

Using some of the strategies mentioned on the other pages can make work more manageable and less exhausting. Getting help with housework and house maintenance, or lowering your standards, can free up valuable energy and time for other activities. If you have young children, sharing how you feel and what affect Parkinson's is having on your energy levels can help them understand, and not feel as if you are neglecting them. You could ask them to prioritise what they would like you to do with them and what they don't mind you missing,

"I am usually too tired on an evening to take you and pick you up from cubs – Jack's Dad has offered to do that but I will still come to football practice every Saturday."

In a similar vein, decide with your spouse what you would like to do together if you have to reduce your social activities, talk things through and come to a decision, rather than just letting things 'go'. Remember that your fatigue may also be curtailing your spouse's social life, so this might be a time for he/she to evaluate his/her own leisure interests and with your persuasion do some things on his/her own.

Be aware that if you eventually do leave work you will need something to do with you time, if you have given up all your leisure interests you might find it hard to re-engage with them.

Work is one of the biggest social opportunities for most people, and some people have mentioned that they feel very lonely when they leave work. Be prepared for this, and ensure that you maintain your network of friends outside of the work environment. This can be hard work and tiring and will probably involve disclosing to them about your diagnosis which might be uncomfortable, but it will mean that your friends will be there to support you and your spouse/family when needed. You might be able to think of strategies to maintain your social contacts.

One man with Parkinson's said that he and his wife had an arrangement to meet up with two other couples to go for a meal every month – this had been happening for years. For two or three months he had been unable and unwilling to go due to fatigue (getting ready to go out, driving, finding somewhere to park and walking to the restaurant left him feeling shattered before the meal had even started!) and he also didn't feel comfortable in a restaurant. When he eventually explained how he felt to his friends they organised that they would meet up at each couple's house and either cook or order in a takeaway. That meant that he didn't have to park and walk, could go as casual as he

liked and still feel comfortable in his surroundings, and it was less financially costly. Most importantly if meant that he and his wife maintained their social contacts.

Some people have said that they feel as if they have lost their identity when they give up work. Taking on more responsibility around the house or swapping roles can sometimes ease the financial pressure and give the person staying at home a purpose, but some people may find this a difficult shift.

Leaving work can mean more time and energy for leisure activities but can also mean reduced finances to pay for those activities! Loss of income may mean that you have to plan for a more financially restricted retirement, but taking advantage of benefits and concessionary rates for leisure activities may help out.

The Parkinson's Disease Society have produced an information booklet about leisure activities which you may find useful.

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Looking Back

When people with Parkinson's were asked about their own experiences of maintaining or leaving employment did they feel on reflection that they had made the right decisions or was there anything they wished that they had done differently? Most people felt that they had made the right decision or were very philosophical about it – below are some comments:

"I feel I made the right decision to keep on working - both for money and for routine."

"So far so good - feel as if I have made the right decisions."

"Regarding leaving work, if I were to do it again I would get a more accurate prognosis of my financial state."

"Yes, I think I did make the right decisions for me but I shouldn't have given up my leisure activities to concentrate on my job."

"I should have found some way of getting more contributions into my pension before I left."

"I should have tried to explain exactly what help I needed – my employer and colleagues might have been a bit more forthcoming if I had."

"I made the right decision to leave I certainly don't miss the stress but I underestimated how much I miss my colleagues."

"I wish I had come to terms with my diagnosis earlier and could have then put my efforts into finding a more suitable job."

"I think I overreacted when I got my diagnosis – I never went back to work! But now my medication is sorted out I feel OK and would love to be back in the work environment."

Helpful tips

Below is a list of advice and tips for people with Parkinson's who are considering their employment options. People who have been through that experience have compiled this list and hope that you find it helpful.

Tell people when you feel it's the right time to tell.

When you tell your employer, explain about PD and that its progress is different for each person - can't predict it's effect on you. Also timescales - ask for periodic reviews at least every 6 months (with HR) so you can explain how you are being affected and what support you need, or aspects of you job you need to change. Work together to find the best course of action.

Be as honest as you can with your employer and colleagues, covering up only increases your stress.

Tell your employer and colleagues as much as possible about Parkinson's.

Ask for help – people can't give it if they don't know what you want.

Ask your employers what they can do for you.

Be positive about what you can do and be honest about what you can't do.

Don't rush into any decisions or overreact into giving your job up.

Don't give in, but rest when you need to.

Before leaving, take some time off work if you need to get advice. Rest, and get things sorted out in your own mind.

Contact your local DEA or job-centre before you leave – they are not just there to help you to find a job, they can help you keep one!

Know what your rights are - don't leave it to someone else. Research all aspects of employment rights.

Check out your pension and contributions – is there any way of getting additional contributions, after all you might be looking forward to a very long retirement!

Contact the PDS for help if you are having difficulty with pensions, benefits or your rights as an employee.

Work for as long as you can. Find ways to help you maintain your employment - support, adaptations or going part-time. It maintains your identity; role, social contacts and the financial aspect shouldn't be overlooked either!

Work as hard as you can for as long as you can to keep your mind active and avoid depression - try to lead as active and normal a life as possible.

If you aren't getting out because you are spending your energy on maintaining employment, make sure that you keep your friends from outside work, otherwise when you leave work you may become socially isolated.

Ask your consultant, GP or PDNS for help.

Accept help – you are entitled to it!

Try and relax! Anxiety can be a real problem and only makes your symptoms worse.

Keep a positive attitude.

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Employer's Guide

This page has been compiled from suggestions made by people who have Parkinson's and their employers.

Just because someone has Parkinson's does not mean that they will be unable to do their job. Some of the symptoms may affect certain aspects of their role, but neither the person with Parkinson's nor their doctor can predict the progression of this condition. The way Parkinson's affects people can be very individual and not everyone will experience all the symptoms associated with Parkinson's, see 'impact on employment' page for more details.

When your employee informs you that he/she has Parkinson's you may in fact be seeing him/her at his/her worst. Often people with Parkinson's have a lot to deal with when first diagnosed – getting used to the diagnosis itself and trying out new medication. This is not a time to be making decisions about the future. A few months down the line may produce a more realistic picture when the initial emotional turmoil has subsided and the medication regime has been sorted out. Your employee will need time and support following his/her diagnosis and the best thing you can do is to encourage him/her not to make any hasty decisions regarding his/her job.

A person cannot be sacked because they have Parkinson's. The Disability Discrimination Act (www.disability.gov.uk/dda/) protects employees rights in this type of situation and as an employer you should familiarise yourself with this legislation. The Disability Rights Commission has information regarding employment law and disabled people www.drc-gb.org/

One of the most useful things you can do is meeting with your employee at agreed regular intervals of between three and six months. This meeting could involve the employee, employer, or/and line manager and someone from the Personnel or the Human Resources department. These regular meetings can enable your employee to identify any particular problems that he/she is experiencing and you can then decide jointly on a plan of action. This pro-active approach can be much more constructive than waiting for a problem to get out of hand.

There is support for both you and your employee if he/she wishes to remain in employment, but is experiencing some problems with carrying out tasks associated with the job. The Disability Employment Advisor (DEA) is an excellent source of help and can be contacted through your local Job Centre (see useful contacts and links). The DEA can help with equipment, adaptations, even providing someone to help your employee carry out his/her job if appropriate, through the Access to Work Scheme www.jobcentreplus.gov.uk/cms.asp?Page=/Home/Employers/DisabilityServicehelpforEmployers/Accessto work

Flexibility is the key in enabling someone with Parkinson's to manage his/her job. Exploring working from home options at least for part of the week can enable your employee to work in a quieter environment with fewer distractions and to be able to work at his/her own pace. It will also help your employee to manage his/her fatigue as it will cut down on travel. Flexibility with start and finish times will allow your employee to work around medication timings and perhaps avoid rush hours. Allowing longer lunch-breaks can enable your employee to 'recharge batteries', providing a resting place is even better!

If your employee is having difficulty with his/her job you could consider allocating tasks that they are unable to do to another person, offer part-time working in addition to the flexibility identified above or offer him/her another position within your organisation. The Employers' Forum on Disability website gives information on best practice and available help for employees with disabilities, including useful fact sheets www.employers-forum.co.uk

Applying for a job – an employer's guide

Some people with Parkinson's have reported that they feel as if they have been treated unfairly when applying for jobs because of their condition and felt it would be useful if a guide was developed for employers particularly when interviewing someone with Parkinson's.

The Disability Discrimination Act (DDA) 1995 makes discrimination on the grounds of disability unlawful. Employers may not discriminate against a disabled person when recruiting, a member of staff. Adjustments should be made so that an applicant with Parkinson's is not placed at a disadvantage in comparison to others.
www.disability.gov.uk/dda/

Someone with Parkinson's may find it easier to fill in an application form electronically – if requested send out an electronic version of the application form.

Due to the fatigue experienced by some people with Parkinson's part-time or job-share options may be preferred.

Due to the timing of medication some flexibility in scheduling the interview would be appreciated so that the interviewee is at his/her best.

When interviewing someone with Parkinson's be aware of the symptoms of this condition that may affect the applicant's performance during the interview:

Dyskinesia – involuntary writhing or jerky type movements, it may look as if the applicant is fidgeting.

Lack of facial expression – may look as if the applicant is not responding to what is said or lacks warmth.

Difficulties with voice – the applicant's voice may be quiet, breathy, and monotonous, or the speech may be slow. This might be interpreted as the applicant sounding boring or slow to respond.

Bradykinesia – or slowness of movement. This might be interpreted as the applicant lacking in dynamism.

Poor posture – slightly stooped when standing or sitting. This might be interpreted as the applicant slouching or failing to make eye-contact.

These symptoms are part of the condition, but the interpretations often associated with them are not! Don't judge the Parkinson's – judge the person!

A person with Parkinson's may require additional help or equipment at work which can be provided by the Access to Work scheme

www.jobcentreplus.gov.uk/cms.asp?Page=/Home/Employers/DisabilityServicehelpforEmployers/Accessto work

The Employers' Forum on Disability website gives information on best practice and available help for employees with disabilities, including useful fact sheets www.employers-forum.co.uk