

**Parkinson's impact on quality of life and cost of care on people with condition and their families in the UK: A review of literature\***

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**Parkinson's impact on quality of life and cost of care on people  
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A review of literature\***

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## Introduction

Parkinson's disease (PD) is one of the long-term conditions largely affecting the older population, currently diagnosed when the part of the brain that controls movement is affected by a deficiency of a neurotransmitter dopamine (motor symptoms), but also evident from the presence of non-motor symptoms such as depression, fatigue and pain that manifest before the motor features (Schrag et al. 2014). There is no cure for Parkinson's, but early diagnosis can help in enabling the person to self-manage their condition through support from health professionals, carers and families (Baker and Graham, 2004).

There are an estimated 127,000 people living with Parkinson's in the UK (Parkinson's UK, 2015), and even this figure is considered a great underestimation. The provision of both health and social care services to address the management of Parkinson's, especially as the condition progresses and as the person ages, has the potential to generate a large economic and financial cost to the individual, to the Government and society. However, there is a lack of research in estimating this total cost in the UK.

As Parkinson's is progressive, with both motor- and non-motor symptoms developing at varied times over the course to the condition requiring different strategies and inputs, the estimated cost for management is large, with a likely substantial imposition on quality of life. Much of Parkinson's care is informal, meaning that the impact on quality of life is not restricted to the individual with Parkinson's, but extends to carers, family, and friends (Williamson et al. 2008).

Given the large, and increasing numbers of people with Parkinson's in the UK, it would be of benefit to understand the cost of care, management and effective treatment available in the UK to the individual with Parkinson's and to society.

The literature review aimed to gather evidence on the impact of Parkinson's on the socio-economic life of individuals with the condition, their families and society based on prior research undertaken in the UK. The review also sought to enable a better understanding of the key medical and non-medical cost components directly associated with Parkinson's management and care, with an understanding of where public resources are currently directed. The literature has been synthesised using a comprehensive and transparent literature review process

## 1. Methods

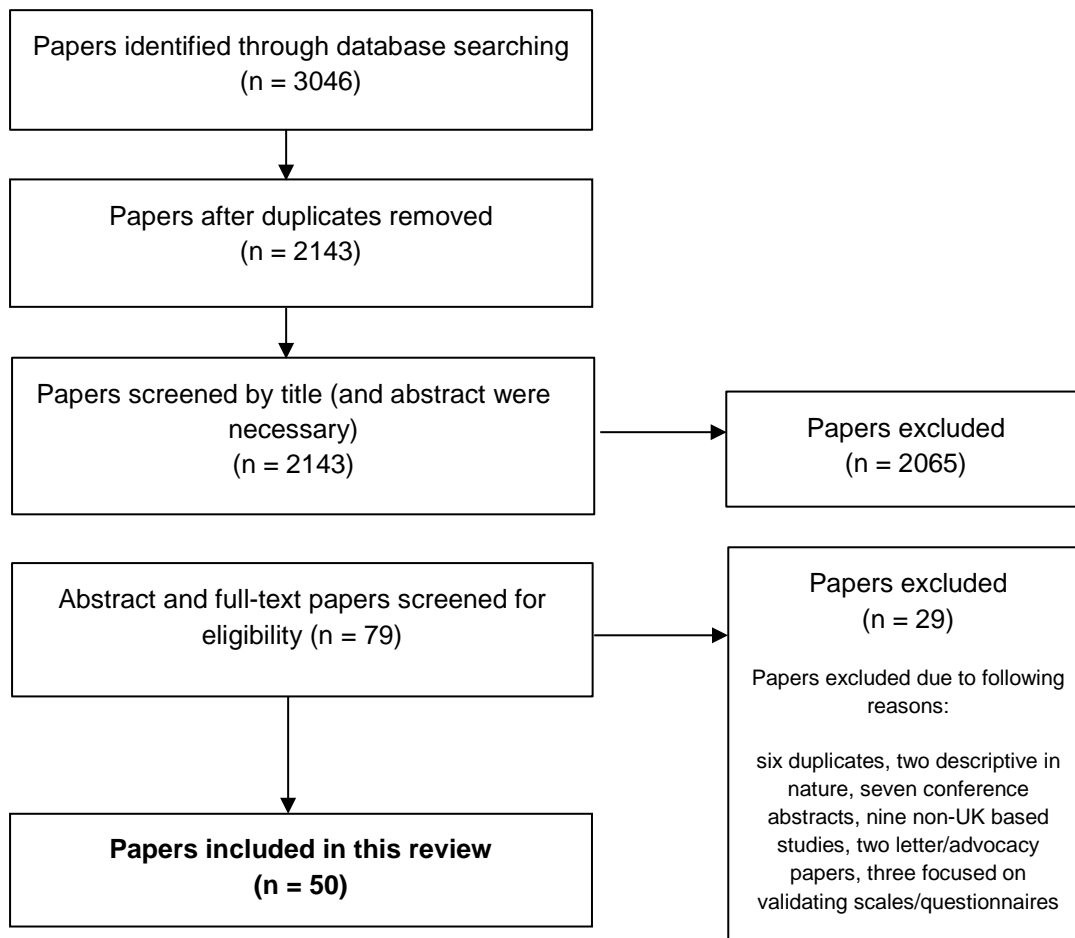
Inclusion criteria: The review searched for published, peer-reviewed papers and grey literature from the UK, which underpins and quantify the direct and indirect impact of Parkinson's on society. Articles published in the English language between 1991 and 2015 were eligible for inclusion. All quantitative and/or qualitative study types were included.

Search strategy: The literature search strategy was developed in consultation with the research team and comprised three facets: (1) terms for Parkinson's, (2) terms to describe the costs associated with the condition, such as financial, employment, pension, housing, healthcare costs, quality of life (QoL), and (3) terms to limit to studies situated in the UK. All terms were searched for in the title and abstract fields and controlled vocabulary terms used where available. The Boolean operators AND and OR were used, alongside truncation, phrase searching and proximity operators. The following databases were searched: ASSIA (ProQuest), CINAHL (EBSCO), Cochrane Library (Wiley), EMBASE (via National Health Service Healthcare databases), MEDLINE (EBSCO) and Web of Science (Thomson Reuters). All search results were exported to RefWorks, a bibliographic management tool. A copy of the search strategy is provided in Appendix 1.

Quality appraisal and study selection: After removal of most duplicate records, the database searches retrieved 2143 papers. In the first instance, the titles of all retrieved papers were screened for relevancy, with abstracts read where necessary. This resulted in a shortlist of 79 papers. A second, thorough screening of the abstracts and full text of all shortlisted papers resulted in 50 papers deemed relevant to this review. The 29 papers excluded at this stage were eliminated for the following reasons: six were duplicates, two were descriptive in nature, seven were conference abstracts, nine were non-UK based studies, two were letter/advocacy/media papers, and three focused on validating scales/questionnaires. The scrutinising and selection of papers for inclusion were carried out by two members of the research team. The literature search screening process is summarised in the flow chart (adapted from Moher *et al.*, The PRISMA Group, 2009) in Figure 1.

Data extraction and synthesis: Papers meeting the inclusion criteria were read and data extracted using a standardised extraction form encompassing: author / date, the focus of the study, research design and sample size. The evidence was grouped into five themes: (a) Parkinson's incidence differentials by socio-economic status, (b) Parkinson's management and care, (c) Impact on QoL and wellbeing of PwP, carers and family members, (d) Cost of healthcare use, and (e) Societal cost of Parkinson's.

**Figure 1: Search one: flow chart of the literature review selection process**



## 2. Studies Included for Review

Final inclusion of papers: A majority of the papers included in the literature review studied the impact on quality of life of PwP, carers and their family members (27 papers). Out of these, 10 papers examined the impact on the health and wellbeing of the caregivers (in the majority of cases, the papers focused on spouses) and other family members. A small number of studies (12) focused on estimating the healthcare costs of Parkinson's, costs to the families of PwP as well as on society. A brief summary of the topics covered by these studies as well as their detailed references are presented in Tables 2 to 5.

Grey Literature Search: Grey literature searches were undertaken on NICE Evidence Search and Google. Grey literature was considered essential to this research and its inclusion is aligned to the comprehensive review methodology, as previously outlined. The inclusion of grey literature also helped minimise publication bias (Booth, Papaioannou and Sutton 2012: p.77). The grey literature searches used an abridged set of search terms; this was due to NICE Evidence Search and Google allowing a limited number of characters. The most salient search terms were identified through a scan of the literature yielded from the database searches. Most identified grey literature studies have already got published and thus duplicated with our previous searches. After screening for direct relevancy to costs of

Parkinson's, the grey literature searches yielded 8 additional resources which merit attention. The key findings from these resources are summarised below (Table 1).

**Table 1: Summary of key messages from grey literature studies**

1.	<u>To detect and serve: DaTSCAN SPECT</u> used to diagnose in cases of uncertainty. Although this approach is costly, it can differentiate a dopaminergic deficit in non-Parkinsonian condition. The tools were benefits to the unnecessary treatment particularly anti-Parkinsonian drugs in people with no dopaminergic deficiency states and peoples 'quality of life.
2.	<u>Protect Parkinson's nurses in England and save the NHS money:</u> Parkinson's nurses had played a significant role in care and help of PwP. Their timely visit and intervention influenced to reduce in avoiding unnecessary consultant appointment, unplanned admission, re-admission, and length of stay in the hospital, thereby saving an additional NHS expenditure of £35.1 million per year. However, there was currently the budget constraint, as a result, Parkinson's nurse service may be decreased in the investment. It meant that PwP were likely to omit delivering vital care from Parkinson's nurses affecting on Parkinson's themselves and their carers.
3.	<u>Royal College of Nursing (RCN) Factsheet: Specialist nursing in the UK:</u> Specialist nurses were significant for patients. They provided tailored care for individual. The Parkinson's nurse can potentially save unnecessary costs in healthcare system of almost £148,000 per year in bed days, £44,000 for avoiding consultant appointments, and £80,000 for unplanned admission.
4.	<u>Medical experts call for hospitals to ensure Parkinson's patients get the right treatment after report reveals they are twice as likely to die compared to other people following A&amp;E admission:</u> PwP were more likely to be admitted as an emergency admission than for planned medical procedures (72% v. 28% respectively). Emergency admissions for PwP costed the NHS annually £200m (£3,338 per PwP as compared to £1,417 for a planned nonemergency hospital stay). The main causes for emergency admissions were pneumonia, physical deterioration, urinary tract infection and hip fractures, and PwP were up to twice as likely to be admitted for these conditions compared to the average patient. Further, PwP were almost twice as likely to stay in the hospital for more than 3 months and almost 2.5 times more likely to die in the hospital after an A&E admission. There is an urgency to ensure that PwP receive the correct, cost-effective interventions to reduce the burden of unplanned hospital admissions.
5.	<u>England hospital Episode Statistics Project:</u> The results from a cross-sectional analysis of England hospital database for 2009-2013 showed 324,055 hospital admissions by 182,859 PwP with the larger figure for non-elective than elective admissions. The share of emergency admission was 72% (costing £777 million). The main unplanned admissions were for pneumonia, motor deterioration, urinary tract infection, and hip fractures. PwP was more likely to stay longer (up to 7 days) at the hospital than their controls; there was also a two-fold share of PwP compared to controls for admission having a length of hospital stay exceeding more than 3 months. Therefore, people affected by Parkinson's should receive an accurate diagnosis of condition to get timely treatment.
6.	<u>Parkinson's Fact Sheet:</u> The number of PwP was approximately 120,000 in the UK in 2011. The manifestation of Parkinson's shows in three main symptoms, including bradykinesia, tremor and rigidity; a diagnosis of Parkinson's is based on having bradykinesia and one or two of the other three symptoms. An autopsy is an absolute approach for the diagnosis of Parkinson's. However, there are tools to help differential states namely PET scan, DaTSCAN, and CT and MRI. Parkinson's has a significant impact on quality of life of both PwP and their carers. This disorder directly affects ability to work thus forcing many PwP to withdraw from

	their jobs and occupation. There is also a tendency to a reduction in working hours for carers. PwPs are also likely to become isolated. The effect of Parkinson's on the socio-economic burden, therefore, affects both the PwP and carers.
7.	<u>Life with Parkinson's Non-motor symptoms</u> : Parkinson's has an economic impact on both direct and indirect costs. The direct costs are presented in terms of medicine and medical care; the indirect costs are associated with loss of employment in person with the disease and also some carers. The major problem occurring in people with Parkinson's is non-motor symptoms that these are not related to the movement difficulty in Parkinson's.
8.	<u>Parkinson's Change Attitudes</u> : The PwP needed assistance for their daily living for instance support from someone (42.8% of PwP), transport (42.8%), motability (40.9%), health treatment (25.9%), and mobility aid (22.0%) and thus resulted in extra money spent per month.
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### 3. Main Findings from Studies

#### 3.1 Incidence of Parkinson's by Socioeconomic Status and Geography

Using Primary Care practices data in North East Scotland, Caslake et al. (2013) estimated the crude annual incidence of Parkinson's at 28.7 per 100,000 persons with a higher incidence in men (21.1) compared to women (14.7). The incidence of Parkinson's has risen exponentially with age particularly post 60 years in both men and women (incidence increased from 11.9 in 50-59 years to 149.3 in 80-89 age group). The overall age-adjusted male- female ratio for Parkinson's incidence was 2.18. However, the incidence didn't significantly vary by level of deprivation in Scotland. Caslake et al. (2013) also undertook a meta-analysis of 12 similar international studies (of which three were UK based). In other UK studies, the estimated Parkinson's incidence which varied between 13.3 and 18.3 was lower than estimated by Caslake et al. study for North East Scotland. Dick et al. (2007) epidemiological study (conducted in four European countries: northern Scotland, south-eastern Sweden, northern Italy and eastern Romania) examined the association between occupational exposure and incidence of Parkinson's. Scottish data showed a non-significant increased risk for agriculture but significantly reduced the risk for 'transport and communication' for developing Parkinson's incidence. However, overall there was no significant relationship between lifetime toxic occupations exposure and incidence of developing Parkinson's.

Horsfall et al. (2013) examined time trends and the influence of socio-demographic and geographic factors on the incidence of Parkinson's diagnosis using UK Primary Care database for patients aged over 50 years. The incidence of Parkinson's varied by age, gender, time period, social deprivation score and urban/rural status. The overall incidence of Parkinson's for people over 50 years was 84 per 100,000 person years. After accounting for socio-demographic factors, the adjusted incidence rates were 46 % higher in men than in women, 12% higher in urban than rural areas and marginally lower in less socially deprived areas. Over time, there was a downward trend in Parkinson's diagnosis with the adjusted incidence rate declining by around 6% every calendar year between 1999 and 2009 which may largely represent changes in diagnosis and/or coding rather than a true decline in incidence. The study concluded that the Parkinson's diagnosis rates in the primary care setting were higher in men and greater in urban areas but not different between socio-economic groups.

**Table 2: UK Studies on Parkinson's incidence differentials by socio-economic status**

<i>Theme and Focus</i>	<i>Design / Sample Size</i>	<i>Reference</i>
1. Socio-economic status (SES) and deprivation (Scotland)	Epidemiological: 377 PwP, meta-analysis	CASLAKE <i>et al.</i> (2013)
2. SES and occupational exposure	Epidemiological: 649 exposed and 1587 controls	DICK <i>et al.</i> (2007)
3. SES and deprivation	Longitudinal: aged 50+ from 469 GP sites. Incidence rates using two case definitions: <u>Broad</u> (6,813 men and 5,929 female), <u>Narrow</u> (5,207 men, 3,844 female)	HORSFALL <i>et al.</i> (2013)
<p><b>References</b>  CASLAKE, R., TAYLOR, K., SCOTT, N., GORDON, J., HARRIS, C., WILDE, K., MURRAY, A. and COUNSELL, C., 2013. Age-, gender-, and socioeconomic status-specific incidence of Parkinson's disease and parkinsonism in North East Scotland: The PINE study. <i>Parkinsonism and Related Disorders</i>, 19(5), pp. 515-521.</p> <p>DICK, S., SEMPLE, S., DICK, F. and SEATON, A., 2007. Occupational titles as risk factors for Parkinson's disease. <i>Occupational Medicine-Oxford</i>, 57(1), pp. 50-56.</p> <p>HORSFALL, L., PETERSEN, I., WALTERS, K. and SCHRAG, A., 2013. Time trends in incidence of Parkinson's disease diagnosis in UK primary care. <i>Journal of neurology</i>, 260(5), pp. 1351-1357.</p>		

### 3.2 Parkinson's Management and Care

Deane et al. (2014) undertook a study with stakeholders (PwP, caregivers, family and friends of PwP, healthcare and social care professionals) to identify and prioritise the top 10 evidential uncertainties that impact on everyday clinical practice for the management of Parkinson's in the UK. After surveying 1000 participants and in-depth discussions, stakeholders agreed on the following top 10 research priorities for Parkinson's management: the need to address motor symptoms (balance and falls, and fine motor control), non-motor symptoms (sleep and urinary dysfunction), mental health issues (stress and anxiety, dementia and mild cognitive impairments), side effects of medications (dyskinesia) and the need to develop interventions specific to the phenotypes of Parkinson's and better monitoring methods. Deane et al. study thus identified crucial gaps in the existing evidence to address everyday practicalities in the management of the complexities of Parkinson's.



Skelly et al. (2015) studied views of consultant geriatricians and neurologists and PDNS on the quality of in-hospital care provided to PwP. The study found wide variations in the standard of care and one-fifth of hospital professionals rated overall standard of care as poor and three-fifths felt that medications were not given on time. The study suggested piloting various interventions to improve the care of PwP in hospitals.

Walker et al (2011) study aimed to assess the PwP health and social care living in North Northumberland (mostly rural area), UK. About 13.3% of PwP were living in institutional care, and remaining 86.7% living in their own homes. Those living at own homes 27.7% had domestic home care services provided and 26.2% used personal home care services. Five PwP had significant care input from a carer or family member (7.7%) and 11 from a care worker (17%). Two patients were regularly visited by a district nurse, one by a social worker, and four by an occupational therapist and two patients regularly attended a local day care centre. The study concluded that living in a rural area appeared to be no hindrance to accessing care services when they were required.

Armitage et al. (2009) undertook in-depth interviews of PwP and their close relatives in care homes to explore the effectiveness of care specifically on the role of family members in implementing care pathway. Five primary themes included were: lack of information about PwP, functional variation, nature of relatives' involvement, care home environment and culture, and care provision. The study found an apparent shortfall in the knowledge and understanding of PwP among care home staff and there was a lack of involvement of PwP family in better management of care.

McLaughlin et al. (2011) explored the caring experience of relatives of PwP for providing palliative care. All 26 caregivers were spouses, the majority female (n=17) and all were responsible for providing physical, social and emotional care in the home. The majority (81%) were aged over 55 years of age and their caring ranged between two and over 20 years. Four themes emerged from the in-depth analysis: medical support for PwP, burden related to caregiving, information needs and economic implications. Although they viewed caregiving as their role and duty, the results highlighted the widespread burden of providing care on the emotional and physical health of the caregivers. The financial implications for providing care were outlined, with many reporting difficulties in accessing benefits. From the point of diagnosis, which had a huge emotional impact on relatives and caregivers, many felt that health professionals hadn't consulted them for the care pathway plan. Since diagnosis, caregivers commented on the lack of continued and coordinated care plans for relatives, resulting in symptoms being mismanaged and care opportunities for family and relatives missed. Stereotypes of the meaning and timing of palliative care were common with many viewing it as being synonymous with cancer and not applicable to a PwP. As the wellbeing of the informal caregiver directly influences the care of the PwP, support interventions are required to relieve their burden, maximise outcomes and ensure targeting of services.

Waldron et al. (2013) examined the social worker's role in the delivery of palliative care to PwP. Differing perceptions of palliative care emerged: from a holistic approach to specialist care near the end of life. Negative associations of palliative care were identified. Other barriers also exist such as a lack of knowledge and experience of Parkinson's and a lack of resources that hinder the delivery of palliative care to clients with chronic conditions. Different interpretations of palliative care affect its delivery to clients with LTC. Very few

PwP were referred to specialist palliative care specifically for management of their symptoms, which must prevent holistic care. Social workers have an important, yet underdeveloped, role in identifying and addressing palliative care needs. Participants stressed that palliative care provision should be extended to support family carers. They felt that the demanding role of a carer often goes unrecognised. Carers, who may have their own health problems, may have to adapt to their loss of independence, increased social isolation, physical exhaustion and psychological stress. They favoured a separate assessment of carers' needs and respite provision for carers that would depend on factors such as clients' level of mobility. Practical help, information, emotional support, referral to appropriate agencies that might be of benefit and respite opportunities were highlighted as carers' needs. Policies and procedures should be clarified regarding prioritisation and access for clients with chronic LTC to appropriate palliative care.

Higginson et al. (2012) examined changes in palliative care needs with Parkinson's in late stage, shown by H&Y stage 3-5. Over two-thirds of patients had a severe disability, over one third being wheelchair-bound/bedridden. Over the year, half of the patients showed either an upward (worsening, 24/60) or fluctuant (8/60) trajectory on palliative care outcome scale and symptoms. The strongest predictors of higher levels of symptoms at the end of follow-up were initial scores on palliative care outcome scale and being male, both were more predictive than initial H&Y scores. The quality of life of PwP in late stage (measured through EuroQuol-5 dimension [EQ5D] and Parkinson's Disease Quality of Life Questionnaire [PDQ]-8 tools) has deteriorated considerably over one year with one-thirds of PwP died. The findings point to profound and complex mix of non-motor and motor symptoms in PwP in late stage. Symptoms are not resolved and half of the patients deteriorate. Palliative problems are predictive of future symptoms, suggesting that an early palliative assessment might help screen for those in need of earlier intervention.

The results have been summarised below (Table 3).

**Table 3: UK Studies on Parkinson's management and care**

<i>Theme and Focus</i>	<i>Design / Sample Size</i>	<i>Reference</i>
1. Priority settings by clinicians, health professionals and families	Cross-sectional: 1000 people	DEANE <i>et al.</i> (2014)
2. In-hospitalisation care: clinicians and health professionals view	Cross-sectional: 93 staff	SKELLY <i>et al.</i> (2015)
3. Care services for rural PwP	Cross-sectional: 75 PwP	WALKER, SWEENEY and GRAY (2011)
4. Effectiveness of care in nursing home	Qualitative: carer's experience: 51 relatives and 24 PwP	ARMITAGE <i>et al.</i> (2009)
5. Palliative care needs, QoL in Late stage	Longitudinal: 82 PwP	HIGGINSON <i>et al.</i> (2012)
6. Palliative care needs, QoL of carers	Qualitative: 26 carer's experience	MCLAUGHLIN <i>et al.</i> (2011)
7. Social workers' role	Qualitative: 13 in-depth interviews of social workers	WALDRON <i>et al.</i> (2013)
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### 3.3 Quality of Life

#### (A) Impact on quality of life and wellbeing of PwP

Parkinson's is a progressive condition and thus has a significant impact on QoL and wellbeing of PwP over time. A number of studies have documented the impact of the progression of Parkinson's into the gradual loss of both motor and non-motor functions, consequently impacting on QoL of PwP. To recognise and factorize specific aspects of impact on QoL and wellbeing on PwP, the eighteen studies identified could be classified into two broad groups: First, Parkinson's symptoms severity and diversity; second, self-help group and social support and their interface with health and wellbeing.

##### 1. *Differential effects of symptoms with Parkinson's stage*

Varied symptoms that emerge from the point of onset of Parkinson's will worsen, particularly in people who have been diagnosed for more than 6 years (Politis et al. 2010). Both the experience of motor (movement) and non-motor symptoms directly affects the QoL of PwP from worry associated with further deterioration in QoL in PwP with condition progression. The Parkinson's Disease Quality of Life Questionnaire (PDQ-39) which covered 8 domains and 39 items, is widely used as a disease-specific measure of health-related quality of life (HRQoL) in PwP. The eight domains included are: mobility, activities of daily living (ADLs), emotional wellbeing, stigma, social support, cognition, communication, and bodily discomfort.

*Motor symptoms:* Bradykinesia, rigidity and tremor are the 'cardinal motor symptoms' affecting the everyday activities and life of PwP. Problematic mobility problems include shuffling gait, start hesitation, freezing, festination, propulsion, and difficulty in turning. The most importance consequence of the motor symptoms is falling, influencing costs related to injury, increased length of hospital stay, and restricting participation in social activities. Motor symptoms were also shown to significantly impact on QoL scores and thus resulted in poorer HRQoL in PwP (Rahman et al. 2008). In comparing the QoL of PwP attending movement disorders clinic vs. general medical clinic in Scotland, it was found that the QoL

of PwP attending the movement disorders clinic was significantly higher (Blackwell, Brown and Rochow, 2005).

*Non-motor symptoms:* Non-motor symptoms manifest in a diverse range of symptoms comprising mood, cognition, sensory disturbance, autonomic disturbance, and pain. The level and degree of non-motor symptoms are correlated to advancing in age and severities of disease. The evidence suggests that these symptoms have a significantly greater influence on HRQoL of PwP from early through to the advanced stages of Parkinson's. Depression, anxiety, impaired concentration, memory retrieval, sleep disturbance, and autonomic disturbance had shown significantly negative impacts on QoL (Findley et al. 2002; Politis et al. 2010; Rahman et al. 2008; Leroi et al. 2011; Duncan et al. 2014; Simpson, Lekwuwa and Crawford, 2014). Depression develops in approximately 50% of PwP as the condition progresses, and although the most troublesome of the non-motor symptoms, remains under-recognised and lacking effective treatment (Politis et al. 2010).

Shearer et al. (2012) evaluated health state utility value affecting motor and non-motor symptoms of patient with idiopathic Parkinson's using the EQ-5D. Findings indicated pain, depression, motor impairment and insomnia as the main declining factors in utility value of PwP. Depression had the greatest impact during the early stage of the condition. Thus an improvement of the main factors influencing utility value could contribute to an increase in QoL among PwP.

In a survey of PwP, the most troublesome symptoms, pain was ranked the highest non-motor symptoms in an early Parkinson's group, affecting the person enough to negatively affect QoL, in particular musculoskeletal and visceral pain (Politis et al. 2010). These symptoms resulted in a direct increase in medical and other health care cost, and should therefore be recognised as a key factor of this disorder, and taken into account for developing further optimal management.

## *2. Self-help groups and social support in PwP*

As Parkinson's progresses, literature highlighted three main alterations PwP encountered in their perception of experience living with Parkinson's: change, addressing changes, and reflections on living with Parkinson's (Benharoch and Wiseman 2004).

First, the most common symptom changes in PwP included tremors, changes in movement quality, dribbling, difficulties in swallowing and speech, tiredness, problem in digestion, and deterioration of memory. Other changes included a decline in mobility, loss of employment, but gains in new skills due to being diagnosed with Parkinson's. Second, the need to address changes identified medications management over time, reactions to other people's involvement, occupations undertaken to maintain wellbeing, and finding new ways of doing things. Third, reflections on living with Parkinson have included thoughts on problems encountered, acceptance of the disease, self-consciousness, the importance of a positive attitude and maintaining normality. PwP who were participating in self-help groups were more likely to accept their condition and also adapt their usual lifestyle. However, they also expected that self-help groups should be more supportive. Conversely, PwP who were not supported socially reported higher scores/levels of distress, anxiety, stress, and less satisfaction (Simpson et al. 2006). Further, those PwP who had stronger social support in terms of number of close relationships had reported relatively much better psychological

outcomes (Simpson et al. 2006). Therefore, further research should be explored into social support and services that might mitigate deterioration in QoL of PwP.

Barrow and Charlton (2002) explored how progression of the condition had affected the lives of eight PwP and whether self-help group membership was related to coping methods (four of the participants were members of the Parkinson's UK Society and four were not). It was found that all participants had experienced losses of physical and mental functioning and independence, self-identity and future and were afraid of further losses as the Parkinson's progressed. Although all participants used a range of coping methods, it was found that there were differences between members and non-members in the prominence of certain methods and overall coping style. For non-members, coping centred upon maintaining a normal life and denying the condition a central role, but for group members, the condition and its likely consequences were accepted and incorporated into everyday life. The discourse of non-members contained many references to a self-help group as a source of distress, while discourse of members identified it as a supportive resource. This exploratory study enhances our understanding of differences between people in their willingness to use a self-help group, and in turn, raises questions about the provision of psychological services in a chronic progressive disorder.

To sum up, the QoL of PwP is mainly affected by non-motor and motor symptoms. Non-motor symptoms include psychological wellbeing, particularly depression and anxiety. Depression is a significant problem affecting PwP yet not well treated leading to direct medical costs and healthcare costs. On the other hand, common motor symptoms derived from bradykinesia, rigidity, and tremors are associated with the physical wellbeing of PwP. These symptoms can provoke a fall associated with injury, treatment in hospital, and additional social care needs. These factors accelerate a reduction in QoL in PwP.

Some studies focused on the impact of Parkinson's on wellbeing. Two studies found poorer QoL and emotional wellbeing in early onset groups than late-onset of PwP (Knipe et al. 2011; Lawson et al. 2014). Another study showed that the subjective wellbeing scores of PwP living in a care home were lower than in people living alone in their own home (Cubi-Molla and Devlin 2014). Moreover, people with advanced Parkinson's experienced a decline in their ability to perform their occupation well due to lower physical, psychological, social and spiritual wellbeing leading to the difficulties with their employment. These caused distress and disappointment of PwP, as well as impacting on their QoL and wellbeing (Murdock, Cousins and Kernohan, 2014).

## **(B) Impact on quality of life and wellbeing of carers and family members**

Parkinson's not only impacted on people who are living with the condition, but also affects the QoL of caregivers, as assessed using PDQ-carer, questionnaire and Short form (SF)-12 questionnaire and self-reported wellbeing questions. Studies have found a number of factors influencing QoL in carers: age, gender, health status, duration of caregiving role, the level of mobility in PwP, and impaired cognitive function in PwP. Most carers were female and were the spouse or partner of the PwP. The caregivers mean age ranged 68-72 years. An increase in comorbidity, particularly psychiatric symptoms, was found almost five-times higher in caregivers compared to the general population of a similar age range. In addition, the QoL of caregivers over the long-term duration of caregiving was inferior compared to the general population particularly in the four dimensions of social, anxiety and depression, stress, and

self-care. Living with PwP had a negative impact on social, psychological, and physical wellbeing in carers. It has been reported that Parkinson's had a widespread impact on caregivers' social, psychosocial, and physical wellbeing (Davey et al. 2004; O'Reilly et al. 1996; Kudlicka, Clare and Hindle 2014; Peters et al. 2011; Peter et al. 2013; Morley et al. 2012; Drutyte et al. 2014). Morley et al. (2012) indicated that carer's age, gender, health status, caregiving duration, mobility and cognitive impairment were significant factors influencing QoL of caregivers.

Schrag et al. (2004) explored the impact of Parkinson's on the offspring of PwP. The activities of daily living help and the loss in social life were main burdens where the children were still in adolescence. In some of adult children, the aspect of caring for their own family was a significant influence. Morley et al. (2011) examined the QoL and wellbeing affecting younger children and older children of parents with Parkinson's and multiple sclerosis (MS). A comparison found that there was no difference in QoL and wellbeing in either groups. Clinical guideline was important for offspring of parental with PD and MS. The NICE guidelines for Parkinson's disease published in 2006, made no reference to the children of PwP; many children who were providing informal care to PwP expressed of not having enough information about their parent's Parkinson's (Schrag et al. 2004; Morley et al. 2011). The future guidelines should include adult children for better communication and interaction with health professional and PwP condition.

Falls in PwP were identified as the most important factor that significantly impacted on informal care, with carers experiencing anxiety, worry, fear, anger, frustration, and shock due to falls in PwP. Increased occurrence of falling in PwP lessened the chances for carers to go out for their normal activities, decreased contact with their friends and neighbours. Furthermore, falling also increased health care costs of PwP and caregivers (Davey et al. 2004). Education courses and support for PwP caring role were limited for informal caregivers, and they need to be supported by health professionals particularly Parkinson's Disease Specialist Nurse (PDNS).

The results have been summarised below (Table 4).

**Table 4: UK Studies on Parkinson's impact on quality of life**

<i>Theme and Focus</i>	<i>Design / Sample Size</i>	<i>Reference</i>
<b>(A) Impact on QoL - PwP only</b>		
1. Physical and mental functioning, independence and self-identity	Qualitative: 8 in-depth interviews of PwP	BARROW and CHARLTON (2002)
2. Positive impact by participation in different daily activities	Qualitative: 7 in-depth interviews of PwP	BENHAROCH and WISEMAN (2004)
3. QoL differentials: attending movement disorder clinic vs. general clinic	Cross-sectional: 42 PwP	BLACKWELL, BROWN and ROCHOW (2005)
4. QoL and Wellbeing differentials	Cross-sectional: 199 PwP	CUBI-MOLLA and DEVLIN (2014)
5. Condition progression (Advanced stage) and treatment	RCT:280 PwP, Sumanirole vs. placebo	DUCHANE and JENKINSON (2003)
6. Non-Motor symptoms at Early stage	Epidemiological: 58 PwP and 99 healthy controls	DUNCAN <i>et al.</i> (2014)
7. QoL differential factors after	Cross-sectional: UK, Italy,	FINDLEY <i>et al.</i>

controlling for disease severity and medication	Spain, USA, Canada, Japan. N=1910 interviews, 203 clinicians and 1020 PwP	(2002)
8. Differentials by young vs older	Cross-sectional: 426 PwP	KNIFE <i>et al.</i> (2011)
9. Early stage cognitive impairment	Epidemiological: 219 PwP and 99 healthy controls	LAWSON <i>et al.</i> (2014)
10. Differentials by Parkinson's stages	Cross-sectional: 123 PwP	LEE <i>et al.</i> (2006)
11. Differentials and predictors	Cross-sectional: 81 PwP	LEKWUWA and CRAWFORD (2014)
12. Early stage - apathy and impulse controls	Cross-sectional: 99 PwP	LEROI <i>et al.</i> (2011)
13. Parkinson's progression	Qualitative: 10 in-depth interviews of PwP	MURDOCK, COUSINS and KERNOHAN (2014)
14. Daily activity - most severe health complaints by Parkinson's progression	Cross-sectional: 130 PwP	POLITIS <i>et al.</i> (2010)
15. Daily activity and management of symptoms/complaints by Parkinson's progression	Cross-sectional: 265 PwP	RAHMAN <i>et al.</i> (2008)
16. Motor and Non-Motor symptoms by Parkinson's progression	Cross-sectional: 162 PwP	SHEARER <i>et al.</i> (2012)
17. Wellbeing and social support	Cross-sectional: 34 PwP	SIMPSON <i>et al.</i> (2006)
<b>(B) Impact on QoL - Carers and Family members</b>		
1. Fall management by carers	Qualitative: 14 in-depth interviews of carers	DAVEY <i>et al.</i> (2004)
2. Stress and financial impact on carers	Cross-sectional: 1881 carers	DRUTYTE <i>et al.</i> (2014)
3. Stress on carers	Cross-sectional: 123 carers	SCHRAG <i>et al.</i> (2006)
4. PwP and Carers by Parkinson's severity	Cross-sectional: 65 PwP, 50 carers	KUDLICKA, CLARE and HINDLE (2014)
5. PwP and Carers by Parkinson's severity	Cross-sectional: 238 PwP-carers	MORLEY <i>et al.</i> (2012)
6. Health and wellbeing differentials Carer spouse vs. non-carer spouse	Epidemiological: 154 carer spouses, 124 non-carer spouses as control	ORIELLY <i>et al.</i> (1996)
7. Health and wellbeing differentials of PwP and Carers	Cross-sectional: 901 PwP, 734 carers	PETERS <i>et al.</i> (2011)
8. QoL and health and social services experience of Carers of Parkinson's vs. Other neurological conditions	Cross-sectional: 1910 carers (434-motor neuron disease, 721-multiple sclerosis and 755-Parkinson's disease)	PETERS <i>et al.</i> (2013)
9. QoL of Offspring	Cross-sectional: 143 offspring	MORLEY <i>et al.</i> (2011)
10. QoL of Offspring	Cross-sectional: 89 offspring	SCHRAG <i>et al.</i> (2004)

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### 3.4 Cost of Healthcare Use

The greatest impact of Parkinson's is on the deterioration of QoL of both PwPs and caregivers. This could also reflect on tremendous economic and financial burden on society in terms of social care and health care delivery costs. The overall economic burden of Parkinson's could be assessed through measuring direct medical and non-medical costs, and indirect costs.

The annual total costs of a Parkinson's case varied markedly between £13,800 (McCrone, Allcock and Burn 2007) and £29,000 (Findley et al. 2011). The direct medical costs estimated to be £1,881 per patient per annum which comprised of hospitalisation (£1,378), professional visits (£385), and test (£117). Direct non-medical costs (professional care costs) were £13,364 per person per annum and indirect costs (informal care costs by families, productivity losses, and sick-leave) ranged between £11,000 and £12,500 per person per annum (McCrone, Allcock and Burn 2007; Findley et al. 2011). The proportions of direct medical costs, direct non-medical costs, indirect costs were 7%, 50% and 43% respectively (Findley, et al. 2011). As seen in the previous figure, the overwhelming costs of Parkinson's were direct non-medical costs and indirect costs. In addition, McCrone, Allcock and Burn (2007) demonstrated that the burden of informal care cost was the greatest, contributing to 80.3% of the total costs of £13804, whilst direct social cost was just 5%. Following on the studies focusing on the impact on caregivers' QoL, data showed that most carers were retired, female and also the spouse or partner of the PwP. McCrone et al. further argued that as most PwP were male, there was underestimation of costs of time put in by female caregivers.

Total costs of care varied by QoL of PwP in relation to medication cycles and condition severity. The severe health states resulted in increasing time spent in OFF state (when medication to improve the dopaminergic system and movement was not at its optimal, and people experienced tremor, stiffness, slowness of movement, and/or mobility problems), with

increasing H&Y scores, and thus resulted in rising costs. Also the longer duration of Parkinson's, depression, gait disturbance, and community/neighbourhood related problems resulted in raising the costs further (Findley et al. 2011). Findley (2007) estimated the total cost of PD between £450 million and more than £3 billion per year; the underlying variation was mainly due to indirect cost and prevalence rate for Parkinson's used in the model.

The hospitalisation occurrences cost the NHS more as compared to ambulatory care. According to hospital admissions data for PwP, 28% were for elective admission and 72% non-elective admission as compared to age and sex-matched individuals admitted to hospital for who the respective proportions were 60% and 40% (Low et al. 2015). Almost double the rate of non-elective admission was found in PwP, with the highest rate (45.3%) recorded in those in the age range between 75-84 years (Low, et al. 2015). The figure of a specific excess bed days (EBD) costs was 12% of total costs (Low et al. 2015). Pneumonia, Parkinson's itself, urinary tract infection, cardiac-related and hip fractures were the most causes of non-elective admissions. The proportion of falls and fractures particularly hip fractures were higher in the total costs (comparison frequencies and costs) (Low et al. 2015). These were consistent with motor symptoms in which falls were the significant troublesome complaint affecting QoL and informal care costs. Furthermore, PwP who had co-morbidities associated with urinary tract infection, pneumonia, hip fractures, were likely to stay longer in the hospital, and in those over 85 years, the likelihood of mortality (death) was higher than the younger age cohorts (Low et al. 2015). Similarly, Xin et al. (2014) found that pneumonia, urinary tract infection, falls and fractures, cardiovascular and circulatory disorders, central nervous system and disorders of sense organs, gastrointestinal disorders, and mental disorder were the main causes for emergency admissions and hospitalisations in PwP with disease progression.

The PDNS can save expenditure towards doctors and specialist consultations on Parkinson's care. According to Hobson, Roberts and Meara (2003) study the PDNS assessed 321 patients and made 881 interventions during one year. The estimated cost saving by employing a PDNS was £54,992. Community visits by PDNS potentially saved £8,296 on outpatient and £1203 on inpatient visits. Jerman et al. (2002) and Hurwitz et al. (2005) examined PDNS intervention and found the nurse specialists had little impact on clinical condition of PwP but improved their overall wellbeing without adding to the PwP's healthcare costs.

A cost-effectiveness and QoL review of Parkinson's undertaken by Dowding, Shenton and Salek (2006) found that carers' burden was the major source for economic costs which so far had not been factored into cost-effectiveness analyses. The study further stated that Parkinson's cost of care including healthcare could significantly be decreased by improving HRQoL of carers. The results have been summarised below (Table 5).

**Table 5: UK Studies on healthcare and societal costs related to Parkinson's**

<i>Theme and Focus</i>	<i>Design / Sample Size</i>	<i>Reference</i>
1. Cost-effectiveness/ QoL reviews	Literature review: International	DOWDING, SHENTON and SALEK (2006)
2. Medication costs differentials by Parkinson's progression	Cross-sectional: 409 PwP, movement disorder clinic	DODEL <i>et al.</i> (1998)
3. Economic and healthcare impact	Cross-sectional: 432 PwP	FINDLEY <i>et al.</i> (2007)
4. Healthcare costs: home vs.	Cross-sectional: 302 PwP	FINDLEY <i>et al.</i> (2011)

residential care	by severity	
5. Healthcare costs by Parkinson's progression	Cross-sectional: 444 PwP	FINDLEY <i>et al.</i> (2003)
6. Specialist Nurse service cost	Cross-sectional: 321 PwP	HOBSON, ROBERTS, & MEARA (2003)
7. Specialist Nurse Intervention on health care costs and QoL	RCT: 1859 PwP	JARMAN <i>et al.</i> (2002); HURWITZ <i>et al.</i> (2005)
8. Hospitalisation costs and incidence	Routine Hospital Episode Statistics data for 4 years	LOW <i>et al.</i> (2015)
9. Hospitalisation costs, incidence by Parkinson's progression	RCT: 2074 PwP, followed over 10 years	XIN <i>et al.</i> (2014)
10. Healthcare and societal costs by severity	Longitudinal: 174 PwP	MCCRONE, ALLCOCK, and BURN (2007)
11. Societal costs - loss of employment	Quantitative: two datasets: 151 and 308 PwP	SCHRAG and BANKS (2006)
12. Employment loss and financial burden	Cross-sectional: 72 PwP	CLARKE, ZOBKIW and GULLAKSEN (1995)
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### 3.5 Societal Cost of Parkinson's

Only a few studies had revealed societal costs of Parkinson's. In terms of (loss of) employment in Parkinson's, the duration since diagnosis of the condition had a direct impact on full-time and part-time work in PwP. The more advanced the condition, the less employment was noted in those populations. Schrag and Banks (2006) study found that in PwP with Parkinson's duration of more than 5 years, only 6-10% of them were working full-time and 7% doing part-time jobs. Further, PwP with more than 10 years since diagnosis had significantly lower employment rate from the first groups. Additionally, the average time loss of employment due to Parkinson's was 4.9 years. PwP between 5 and 10 years since diagnosis stopped working 46% and 82% respectively although gender, type of work, and living circumstances had the least influence on average years of employment loss (Schrag and Banks 2006). McLaughlin et al. (2011) through in-depth interviews with caregivers had outlined the financial implications for providing care to PwP by family members and underlined the difficulties in accessing benefits and loss of income.

Clarke, Zobkiw and Gullaksen (1995) studied the QoL and care of PwP attending movement disorders clinic in England and found that the main problems of care was related to accommodation, travel, holidays and hobbies. They also found financial difficulties arose amongst PwP due to involuntary early retirement and delay in getting welfare benefits. PwP were satisfied with their hospital care, specialised clinic and PDNS input. It was suggested that the need was to strengthen the roles of physiotherapists, speech therapists, specialist nurses and social workers in the management of Parkinson's, as well as value more carer support needs including respite care. Drutyte et al. (2014) found an important stressor amongst carers was a reduced household income as due to caring for the PwP, 25% of carers had reduced their employment and 30% also experienced a reduction in their financial conditions.

There was a significant correlation between the H&Y score for Parkinson's and direct economic costs of health and social care with the more advanced stage of the condition leading to increased direct cost particularly that of social care. These costs by stages varied as follows: stage 0 and I, II, III, IV, and V (£2,971, £3,065, £6,183, £10,134, and 18,358 respectively) (Findley et al. 2003). Those PwP who were in later stages of Parkinson's were likely to become non-responsive to medication (or develop drug resistance) and thus aggravate the condition, leading to increased expenditure on health and social care. Furthermore, the difference in type of accommodation was a significant variant of the cost of care. People who were living in their own home (compared to those in a nursing home) had the lowest total of annual direct costs (£4,189). Costs for PwP living full-time in institutional care were almost fivefold higher than PwP living in their own home (Findley et al. 2003).

## 2.4 Conclusion

Parkinson's is an incurable, long-term, neuro-degenerative condition with movement, cognitive, psychological and physiological symptoms that have a substantial impact on QoL, especially as the condition progresses particularly as an individual becomes less able to look after him or herself. In many cases, Parkinson's care is informal, as family members and friends take on a carer role assisting the PwP. Indeed, the vast majority of the cost of managing Parkinson's has been attributed to informal care and social care, rather than direct medical costs. The literature clearly highlights that not only does the QoL of PwP deteriorate over time but the QoL of their family members and carers are also severely affected – both in economic and social contexts. Family members gave up their time, employment and resources, plus watched the deterioration of the QoL of people they cared for; thus accentuating the total societal costs. Grey and published literature has also highlighted the critical role played by Parkinson's nurses in the management and care of Parkinson's, and reiterates that additional funding by the NHS should be allocated for strengthening and extending outreach services of Parkinson's nurse specialists (and possibly other health and social care specialists) to PwP and their families.

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## Appendix 1: Search Strategy

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### Pilot searches in MEDLINE (EBSCO)

The searches have been written up for MEDLINE using the EBSCO interface and are detailed below.

Explanation of search terms used: ti = title field; ab = abstract field; af = author affiliation field; / = controlled vocabulary term; exp. = controlled vocabulary term exploded; asterisk (\*) = denotes any character; "" = phrase search; n = proximity operator.

1. parkinson\*.ti,ab
2. parkinsonian disorders/
3. parkinson disease/
4. or/1-3
5. cost\*.ti,ab
6. financial.ti,ab
7. finance\*.ti,ab
8. fiscal.ti,ab
9. economic\*.ti,ab
10. socio-economic\*.ti,ab
11. wage\*.ti,ab
12. expenditure\*.ti,ab
13. debt\*.ti,ab
14. income\*.ti,ab
15. saving\*.ti,ab
16. employment\*.ti,ab
17. unemployment.ti,ab
18. pension\*.ti,ab
19. housing.ti,ab
20. salary.ti,ab
21. salaries.ti,ab
22. paid.ti,ab
23. outlay.ti,ab
24. outgoings.ti,ab
25. expense\*.ti,ab
26. price\*.ti,ab.
27. spending.ti,ab
28. earn\*.ti,ab
29. budget\*.ti,ab
30. payment.ti,ab
31. burden.ti,ab
32. sacrifice.ti,ab
33. deprive\*.ti,ab
34. "quality of life".ti,ab
35. carer\* N3 health.ti,ab
36. carer\* N3 impact.ti,ab
37. carer\* N3 "well being".ti,ab
38. carer\* N3 wellbeing.ti,ab

39. carer\* N3 "quality of life".ti,ab
40. family N3 health.ti,ab
41. family N3 impact.ti,ab
42. family\* N3 wellbeing.ti,ab
43. family\* N3 "well being".ti,ab
44. family\* N3 "quality of life".ti,ab
45. families N3 health.ti,ab
46. families N3 impact.ti,ab
47. families N3 "well being".ti,ab
48. families N3 wellbeing.ti,ab
49. families N3 "quality of life".ti,ab
50. caregiver\* N3 health.ti,ab
51. caregiver\* N3 impact.ti,ab
52. caregiver\* N3 wellbeing.ti,ab
53. caregiver\* N3 "well being".ti,ab
54. caregiver\* N3 "quality of life".ti,ab
55. cost of illness/
56. costs and cost analysis/
57. health care costs/
58. health expenditures/
59. direct service costs/
60. hospital costs/
61. drug costs/
62. cost savings/
63. financial support/
64. financial management, hospital/
65. financial management/
66. economics/
67. models, economic/
68. economics, hospital/
69. socioeconomic factors/
70. salaries and fringe benefits/
71. employment/
72. health expenditures/
73. income/
74. pensions/
75. housing/
76. quality of life/
77. or/5-76
78. "united kingdom".af
79. uk.af
80. britain.af
81. scotland.af
82. england.af
83. wales.af
84. "northern ireland".af
85. exp. great britain/
86. england/
87. northern ireland/
88. exp. scotland/

89. wales/
90. channel islands/
91. guernsey/
92. or/78-91
93. 4 and 77 and 92
- 94.

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## Grey literature searches

### **NICE Evidence Search = 1015 results**

((parkinson\*) AND (cost\* OR financ\* OR economic\* OR expenditure\* OR debt\* OR income\* OR pension\* OR salar\* OR spending OR earn\* OR budget\* OR burden OR sacrifice OR "quality of life" OR carer OR famil\* OR caregiver))

*This search was shortened as the number of characters allowed was limited. The results were also limited to anything published in the last three years.*

### **Google.co.uk = 36,700,000 results**

((parkinson\*) AND (cost\* OR financ\* OR economic\* OR expenditure\* OR debt\* OR income\* OR pension\* OR salar\* OR spending OR earn\* OR budget\* OR burden OR sacrifice OR "quality of life" OR carer OR famil\* OR caregiver))

*This search was shortened as the number of characters allowed was limited.*