Written evidence submitted by Parkinson's UK (ELC0082)

About Parkinson's

1. Parkinson's is a, fluctuating, degenerative neurological disorder. Despite advances in treatment, there is no known cure.

2. The pattern of decline in Parkinson's, as in other neurological conditions, is different from the typical progression towards death seen in cancer and organ failure. Services need to be designed for an advanced phase that lasts, on average, 2.2 years[1], and are flexible enough to provide appropriate support to people with Parkinson's and their carers as their needs fluctuate and change.

3. The advanced stage of Parkinson's can be marked by pain, fatigue, problems with swallowing, first aspiration pneumonia, breathlessness, weight loss, continence issues, frailty, marked decline in physical function, immobility, falls, recurrent infections, weight loss, mental health problems and dementia.[2] [3] It is also very common for people with advanced Parkinson's to have other serious health conditions, that, combined with the fluctuating nature of Parkinson's can make it harder to recognise that they have reached the end of their life.

4. People with Parkinson's have up to six times the population risk of developing dementia. Up to 80% of people who have lived with Parkinson's 10 years or more may develop dementia.[4] Given the high risk of losing mental capacity for serious decisions about end of life care – including where they would like to die and choices about life-sustaining treatment, such as resuscitation, respiratory support, medication, artificial nutrition and hydration - people with Parkinson's should have an opportunity to express their priorities and preferences and make plans as soon after diagnosis as they want to.

5. Although people may not die from Parkinson's, the condition increases the risk for direct causes of death such as aspiration pneumonia. Most people's life expectancy is not greatly reduced because of Parkinson's. However, some of the more advanced symptoms can lead to increased disability and poor health, making the person with Parkinson's more vulnerable to infection.

6. Parkinson's UK believes that with appropriate care and support, many people with Parkinson's can have a good quality of life for many years after diagnosis. We believe that people with Parkinson's, their carers and families should be able to exercise their right to access effective health and social care services at every stage of the condition, including at the end of life. This should always involve timely provision of good quality information so people know what support is available at every stage and how they can access it.

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[1] Richfield et al, Palliative care for Parkinson's disease: A summary of the evidence and future directions, 2013.

[2] Richfield et al (2013).

[3] Higginson et al, Symptoms and Quality of Life in Late Stage Parkinson Syndromes: A Longitudinal Community Study of Predictive Factors, 2012.

[4] Perez et al, Risk of dementia in an elderly population of Parkinson's disease patients: A 15-year population-based study, 2012.

7. Parkinson's UK recognises that everyone affected by Parkinson's experiences the condition differently, and acknowledges that individuals affected by the condition hold a wide range of personal beliefs about end-of-life decisions: some people with Parkinson's may wish to refuse certain interventions, while others may request them.

8. We believe that everyone with the condition should be given the opportunity to exercise their right to make decisions about end-of-life care in good time, and that their decisions and wishes should be at the centre of their care.

9. We support the NICE clinical guideline on Parkinson's[5] recommendation that people with Parkinson's should have access to palliative care and support from the point of diagnosis onwards, with a broad definition of palliative care, such as the one developed by World Health Organisation: *"The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with … treatment.*"[6]

10. As a charity we offer education services for professionals, self-management and information and support services for people with Parkinson's and their carers in order to underpin excellent palliative care and also help with issues surrounding end of life in terms of identification of needs and preferences.

Executive summary

11. Parkinson's UK welcomes the committee's inquiry and would be delighted to provide further written and or oral evidence.

12. This submission addresses the following issues:
    a. Advanced care planning
    b. Where people with Parkinson's die
    c. Prognostic and integrated approaches to palliative and end of life care in Parkinson's
    d. Funding mechanisms for end of life care, particularly focusing on NHS continuing healthcare
    e. Free social care at the end of life

Advanced care planning

13. Research demonstrates people with neurological conditions, including Parkinson's, are much less likely to have opportunities to take part in advance care planning, or to receive specialist palliative care and end-of-life support than people with cancer.[7] [8] This is despite the levels of symptoms and problems being similar to or more severe than, those entering palliative care with cancer.[9] This suggests that palliative care is not being

[5] NICE clinical guideline 35, Parkinson's Disease: Diagnosis and management in primary and secondary care, 2006.
[6] World Health Organisation (1990) Cancer pain relief and palliative care. Technical report series 804. Geneva: WHO.
[7] Harrison et al, Are UK primary care teams formally identifying patients for palliative care before they die?, 2012.
[8] Walker, Palliative care and end-of-life planning in Parkinson's disease, 2013.

equitably offered to all those in need.

14. Advanced care planning is essential for effective palliative and end of life care for people with Parkinson's owing to the high risk of developing Parkinson's dementia and the physical complications that lead to death. We understand from our members across the UK that advanced care planning is not consistently offered. This is unacceptable and inevitably leads to great distress for the patient and their loved ones.

15. Once a person is identified as having a terminal illness, advance care planning is crucial. It is particularly important for people at a high risk of dementia, like people with Parkinson's, who may lose mental capacity as their condition progresses.[10]

16. We are aware that health and social care professionals can find it difficult to broach issues related to end of life wishes, particularly when a service user's future is uncertain, as it is with a condition with an unpredictable profile, such as Parkinson's. We would therefore urge appropriate professional associations and healthcare training bodies to provide guidance and support for their staff in helping people affected by Parkinson's to make choices and assert control even in situations of uncertainty. Also we would encourage staff to be proactive by asking about changes in thinking or behaviour that point to the onset of dementia.

17. People with advanced Parkinson's commonly experience communication difficulties, making it harder to make their wishes known. Mental health issues including depression and dementia are very common.[11] This may mean that the person with Parkinson's is not defined as legally competent to make decisions, although a diagnosis of dementia or depression does not automatically mean that a person does not have mental capacity.

18. The Care Quality Commission's inspection programme is uncovering a widespread lack of understanding about how to apply the Mental Capacity Act[12] – and Parkinson's dementia can have a fluctuating effect on cognitive abilities. We would therefore urge providers of services to people with advanced Parkinson's, including hospitals and care homes, to provide training about how to apply the Act.

19. In later stages of the condition problems with swallowing, sometimes combined with cognitive impairment can make interventions such as the insertion of a percutaneous endoscopic gastrostomy (PEG) tube for nutrition very challenging. Particularly if, as in most cases, the person with Parkinson's has not previously expressed their views upon this while they still maintained capacity to make decisions.[13]

20. Clear and sensitive communication is absolutely essential if advanced planning is to be effective. Parkinson's UK members have raised *'do not resuscitate orders'* as one area

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[9] Higginson et al, Symptoms and Quality of Life in Late Stage Parkinson Syndromes: A Longitudinal Community Study of Predictive Factors, 2012.

[10] Alzheimer's Society, Living and Dying with Dementia, 2014.

[11] Goetz et al, Treatment of depression in idiopathic Parkinson's disease, 2002.

[12] Care Quality Commission, 2013 http://www.cqc.org.uk/content/cqc-finds-mental-capacity-act-not-well-understood-across-all-sectors-and-calls-more-work

[13] Walker, Palliative care and end-of-life planning in Parkinson's disease, 2013.

where communication and sensitivity has broken down. In some instances the order is broached inappropriately, but in others GPs have refused to sign them for someone with advanced Parkinson's (Appendices 1 and 2). We believe this is an area that should be addressed by the committee.

21. We believe, in accordance with the General Medical Council's guidance,[14] that failure to offer the option to discuss prognosis and care plans with a person and their relatives or carers is unacceptable practice. This leads to untold levels of distress that severely impact relatives' and carers' experiences of the dying process and subsequently their bereavement.

Where people with Parkinson's die

22. It is widely assumed that people with Parkinson's prefer to die at home[15]. However, studies suggest that they are most likely to die in hospital. We believe more needs to be done in communicating wishes in the early stages of the condition and funding community services to allow those who wish to die at home, to do so with dignity.

23. In a study of the medical notes of all people with a diagnosis of Parkinson's living in two adjacent areas of northeast England and who died over a 3-year period it found the majority of people with Parkinson's die in hospital.[16]

24. Of the patients analysed, 47% died in hospital, 24% at home and 25% in a care home. For those who died in hospital, only three patients, and seven relatives of patients, had recorded a discussion with a clinician about their preferred place of death and only 14% were referred to a specialist palliative care team.

25. Analysis of English mortality data has shown that of more than 49,000 people who died with Parkinson's mentioned on their death certificate, only 9% died in their own home.[17]

26. Furthermore, while we wholeheartedly support the right of a person to die at home, we emphasise that the right must be backed up by sufficient investment in community services in order for this to be realised. As Parkinson's is a complex condition, it is important that services are commissioned and managed in a multidisciplinary way, so that skills from the domains of neurology and palliative care, as well as speech and language therapy (swallowing) and all the other necessary therapy areas can be brought together to provide holistic support across all settings. We are concerned that the decommissioning of specialist Parkinson's nurse posts, in favour of generic neurological posts will reduce the quality of care for people with Parkinson's.

27. There is a need for appropriate staffing (staff ratios and skill mix), effective clinical leadership, information gathering (GP registries) and information sharing protocols and systems. Evidence from North East Tyneside shows that where these are in place,

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[14] General Medical Council, Treatment and Care towards the end of life: good practice in decision making, 2010.

[15] Walker, Palliative care and end-of-life planning in Parkinson's disease, 2013.

[16] Walker, Palliative care in people with idiopathic Parkinson's disease who die in hospital, 2014.

[17] http://www.endoflifecare-intelligence.org.uk/resources/tools/ - click on Deaths from Neurodegenerative Diseases in England, 2002 to 2008

quality of end of life care improves markedly. We urge the Department to support the dissemination of this good practice widely.[18]

A prognostic or integrated approach to end of life and palliative care in Parkinson's?

28. Parkinson's UK advocate for an integrated, rather than prognostic approach to identifying and managing palliative and end of life care needs for people with and affected by Parkinson's. We also believe that carers and former carers should play an active role in planning both the care for individuals and the development of palliative and end of life services.

29. In February 2015 Parkinson's UK will be leading the launch of a network[19] of health and social care professionals to share good practice and improve the quality of Parkinson's services across the UK. Palliative and end of life care will be a topic the network looks at developing expertise to improve practice for everyone affected by the condition.

30. The prognostic approach may be less appropriate in chronic, progressive neurological condition as it is difficult to establish when a person is reaching the end of life through this model.[20]

31. Integrated models of care recognise the potential for specialist palliative care to benefit patients from the time of diagnosis and the fluctuating nature of palliative need. Parkinson's UK strongly believes that integrated care should be delivered by a person's multi-disciplinary team (MDT) as a matter of course throughout a person's care journey. This requires monitoring and recognition of unmet palliative care need, identification of triggers for specialist referrals and close working between neurological and specialist palliative services. Over time, as the MDT's skills are developed, the need for specialist referrals should decrease as they are more used to factoring in this care need.

32. It is essential as part of this model for a person's family, loved-ones and carers to be effectively consulted and enabled to maintain their relationships and also provide comfort, support and the elements of practical care they can. Carers and family members of those with Parkinson's are often the experts in their loved-ones condition regarding symptoms, fluctuations and medications timing.

33. Carers often provide the bulk of personal care and are an important source of continuity, as well as a resource with knowledge of the person's needs, wishes, values and preferences. At the same time, carers must not be forced into the caring role. Those who do take on significant caring responsibilities should be supported through peer support and training, including how to recognise and cope with the final phase of the condition and access adequate respite care.

34. We would also acknowledge that family members recognise and monitor changes in their relative with Parkinson's on a daily basis and can therefore help identify the end of life phase to health and social care professionals.[21]

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[18] Dr Kathryn Hall, Presentation at National Council for Palliative Care - Care Planning and Dementia Conference, 10 December 2014

[19] Parkinson's UK, 2014 http://www.parkinsons.org.uk/content/uk-parkinsons-excellence-network

[20] Richfield et al, Palliative care for Parkinson's disease: A summary of the evidence and future directions, 2013

Funding mechanisms for end of life care: NHS continuing healthcare

35. NHS continuing healthcare is an NHS funding package designed to provide free healthcare for all those who are eligible. The system however is shrouded in mystery, leaving thousands of vulnerable and sick people with no choice but to pick up the cost of specialised care they cannot live without – with those living with long-term, degenerative conditions particularly at risk.

36. In the wake of growing concerns regarding the provision of NHS continuing healthcare, the All Party Parliamentary Group (APPG) on Parkinson's, conducted the first-ever Inquiry into the ailing system.[22] The Failing to Care Inquiry found the system was not fit for purpose and subsequently Parkinson's UK launched the Failing to Care campaign to drive essential improvements to the system. (Appendix 5).

37. As the Barker Commission[23] acknowledged in its interim and final reports, NHS continuing healthcare illustrates most 'acutely' the failure in the fault lines between the health and social care system. Ultimately, NHS continuing healthcare is a zero sum game where those found eligible are not subject to often financially crippling care fees, whereas those found ineligible are often forced to sell their home in order to pay for care. The cost incurred to the NHS, currently around £3 billion, and social services of paying for this care often leads to a great deal of cost shunting between the organisations at the expense of the individual's care.

38. This often leads to great delays and as our inquiry demonstrated, some people even die waiting to get a decision on their eligibility (Appendices 3 and 4) This is understandably extremely distressing for their families and can leave people with inadequate care at the end of their life.

39. Several people even reported to the inquiry that they had been told that in order to be awarded NHS continuing care, a person had to be 'practically dead'.

40. We are therefore aware from Marie Curie that the delays experienced through the standard NHS continuing healthcare application are also evident in fast-track applications. This is equally unacceptable, especially considering that a fast-track award would only be made if a person was considered to be in the end of life phase.

41. We are calling on the Government and the NHS to make essential changes to the system without delay (Appendix 5).

Free social care at the end of life

42. Parkinson's UK has been involved in the discussions concerning the development of the policy for free social care at the end of life. We strongly support the principle of free

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[21] Hubbard et al, Recognition by family members that relatives with neurodegenerative disease are likely to die within a year: A meta-ethnography, 2011.

[22] APPG on Parkinson's, *Failing to Care: NHS Continuing Care*, November 2013: http://www.parkinsons.org.uk/sites/default/files/failingtocare_appgfullreport.pdf

[23] Commission on the Future of Health and Social Care in England, A new settlement for health and social care, 2014.

social care at the end of life for people with Parkinson's and the Barker Commission interim report's recommendation for '*making more of the most acute end of social care free at the point of use – for example… Parkinson's disease'*, as we believe this will help people to stay in their own homes for longer. However we are concerned this does set up another funding system rather than address the existing arrangements.

43. One suggestion for identifying end of life which was raised in Ministerial and Department roundtables was to use the DS1500 form to identify the last six months of life. However, this form is not widely used in neurological conditions – even for conditions such as motor neurone disease, which is recognised as a terminal condition. We are concerned that this would make it even less effective for people with Parkinson's, which is not defined as a terminal condition.

44. Further suggestions include referring those who were deemed ineligible for the NHS continuing healthcare through the fast-track mechanism to free social care at the end of life. However, we have also detailed the issues with this route in point 40, above.

45. At the most recent meeting, there had yet to be a suggestion that in our view would truly help all people with Parkinson's who are reaching the end of life phase. As this cohort of people are often the most neglected through the NHS continuing healthcare process, a further failed policy would only add to the emotional and physical distress. We would therefore recommend much greater evidence is considered so that free social care at the end of life benefits people with neurological conditions and not just those with a diagnosis of cancer.

46. Finally, Parkinson's UK has reservations about implementing a further funding mechanism for end of life care in addition to the existing social care criteria and NHS mechanisms discussed above, without first resolving the failures of these existing systems. We recommend the Department and politicians look holistically at funding mechanisms for end of life care, to find truly integrated health and social care solutions to the existing problems, before attempting to implement another funding stream on top of an already confusing and ineffective system.

Conclusion

47. For there to be effective palliative and end of life care for people with Parkinson's we recommend:

    a. The NHS provides access to palliative care from diagnosis, as recommended in the NICE guideline of Parkinson's. This needs to be delivered in a sensitive and effective manner in order to facilitate the best care for people with Parkinson's throughout timely management of the condition, and so that they have had the opportunity to plan for their end of life wishes to be met.

    b. The NHS takes an integrated approach to managing and identifying palliative and end of life care needs for people with Parkinson's.

    c. Essential improvements are made to the NHS continuing healthcare system as a matter of urgency to enable a stress-free, effective assessment and those who are eligible are not forced to sell their property for care that should be free.

d. The Government and Department should address the end of life care funding mechanisms holistically in a bid to effectively redesign current ineffective arrangements rather than implement a further funding route.

Appendix

Appendix 1: Delma Barrett ‘do not resuscitate’ case study

Mrs Barrett’s husband, Chris had advanced Parkinson’s (after having Parkinson’s for 20 years), in addition to heart failure, a couple of strokes and unrelieved arthritis. The couple had conversations with their GP and requested that Chris should not be resuscitated if his heart stopped beating.

While the GP verbally agreed to this, he did not provide the relevant documentation Mrs Barrett later discovered, as he did not feel it was appropriate at that time. However, the GP did not mention this before Chris passed away.

At a restaurant on 2 December 2012, Chris became unresponsive. Initially, Mrs Barrett thought he might have been choking because swallowing had become a problem for him so she asked for an ambulance to be called. Two restaurant staff, recently trained in resuscitation, tried to revive him despite her asking them not to.

When the ambulance arrived the paramedics restarted his heart, against Mrs Barrett’s wishes. She reports ‘I knew he was darn well dead; he was going black.’ Mrs Barrett had worked in ICU and operating theatres. The paramedics apologised for having to keep on trying against Mrs Barrett’s wishes but stated (correctly) that without documentation they would not be able to respect this wish.

When Mr Barrett was in intensive care, the consultant agreed to remove the tube from his airway. It took Mr Barrett two days of ‘heaving and heaving for breath’ to die, which he eventually did on 4 December 2012, after he was given a muscle relaxant.

Mrs Barrett was not made aware by any healthcare professional that she required official documentation that needed to be on her person should Chris become unresponsive. When she discovered this, she wrote to her local ambulance service and MP and spoke with her GPs because she wanted to understand and raise awareness of the issue of resuscitation when people do not wish it to take place.

Appendix 2: Martin King ‘do not resuscitate’ case study

During a conversation with his GP, Mr King was asked whether in the event of becoming unresponsive, he would like to be resuscitated. Mr King stressed he is very happy with his GP, but feels that the situation should have been more sensitively handled.

Mr King’s GP told him he was in the top 2% of his patients most likely to be admitted to hospital, and therefore had to be asked about his wishes regarding resuscitation, and various other matters.

Mr King believes that the intention of this questionnaire was to flag up support services in the home to prevent/delay, hospital admission for the elderly and those with chronic conditions. He said:

“Without context I was asked in a matter of fact way, about mobility in a similar way to that of other welfare allowances which one would normally have the benefit of someone there to support you.

“Further questions included what support did I think I needed and out of the blue came this question, ‘where would you prefer to die at home or hospital?’ and ‘would you indicate if when you die do you want to be resuscitated?’.”

In the first instance Mr King was taken aback and said he would not like to be resuscitated. But in the hours following the conversation became unhappy with the ramifications of his decision and subsequently reversed his initial decision. Mr King believes there should have been a much more sensitive approach adopted in asking people this question, a ‘cooling off’ period after the conversation has taken place and more consideration of the circumstances concerning the point of death.

Appendix 3: Leslie Goff NHS continuing healthcare case study
When Leslie Goff ’s health declined rapidly, he needed round-the-clock nursing care.

The pensioner, then 82, was bed-bound with Parkinson’s and should have been entitled to NHS continuing healthcare. But his wife Doris and son David became locked in a battle with their health authority. In at least three cycles of assessments and meetings, they were repeatedly assured he was eligible, only to be told by separate panels that they needed to provide more information.

All the while, Mrs Goff, who is now 78, was paying around £1,600 a month from the couple’s savings for her husband’s nursing home fees.

Mr Goff died aged 83, in March 2011 ‘without a penny’ having been provided by his local health authority in east London.

Son David, 40, offered to abandon his claim for the full cost of care – around £18,000 – if they would pay for the final 12 weeks. ‘They agreed straight away,’ he said. The authority refunded the family just over £4,000.

Appendix 4: Julie Hill NHS continuing healthcare case study
“NHS continuing healthcare was initially granted to my mother, who had advanced Parkinson’s, in May 2005 but was withdrawn in August 2009 with no explanation as to why she had failed to qualify, no mention of an appeals process and no one to reply to my frantic calls. She had clearly deteriorated from when she was initially given funding and had a team of seven specialists caring for her. For the next two years we had to fight the PCT to get the funding back that we always knew we were entitled to. This took a dreadful toll on my husband and I, both mentally and physically. My husband has Parkinson’s too and I was also fighting kidney cancer, so the impact of battling the PCT took everything out of us. By the end of it my husband was suffering from depression and my nerves were absolutely shredded. During the two year fight we had to pay for the care ourselves from our savings, through my husband’s disability benefits payments and accruing debt against my mother’s property. After an awful two years of being intimidated, stone-walled and victimised by the PCT we were offered an apology and all the funding for that period. Unfortunately my mother died just two weeks after this. The worst thing of all was that those last precious years with my mother were stolen from me. I should have been enjoying the time left with her but instead I was doing mounds of paperwork and staying up until 3am every night for months on end trying to get my head round the system. It was appalling.”

Appendix 5: Failing to Care inquiry and campaign

NHS continuing care is a package of care that is arranged and funded by the NHS and is free of charge to the recipient. It can be provided in residential homes, hospital, a hospice or in a person's own home. The decision for eligibility is not based on a condition but on whether the care need is primarily due to the individual's health issues. In England, Scotland and Wales, the primary health need is defined in specific published guidance, whereas in Northern Ireland, decisions are made locally by the health and social care trusts.

The complex health needs that people with advanced Parkinson's have mean that some people are likely to meet the criteria for NHS continuing care. Motor symptoms such as tremor, muscle rigidity and slowness of movement and commonly occurring non-motor symptoms including difficulties with balance, incontinence, difficulties swallowing, pain and mental health problems such as dementia and hallucination may be of such a nature to indicate a primary health need. In the wake of growing concerns from callers to our helpline, Parkinson's UK and the All Party Parliamentary Group on Parkinson's conducted the first ever inquiry into NHS continuing care.

The final report published in November 2013 found that the system was not fit for purpose. People giving evidence to the inquiry explained:

- Due to a lengthy process, people with Parkinson's are dying whilst waiting for their health board to make a decision on whether they are eligible
- The majority of assessments did not involve a professional with specialist expertise or knowledge in the condition – leading to inaccurate and incorrect decisions on funding
- All of the health and social care professionals we spoke to admitted the system is so complex they have difficulty following the correct process
- 40% of people going through the assessment process reported experiencing a lack of empathy and transparency from professionals, in the decision making process and in appealing against a decision
- People with Parkinson's were continually reassessed and often found to have 'got better' leading to funding being withdrawn, despite having a progressive condition
- There were clear examples of existing national guidance not being followed either in the length of assessment or in how the decision is made, with no repercussions for breaches
- A lack of local NHS performance data meant that the Department of Health is unable to tell if and where issues are occurring.

There are several areas that NHS England must immediately address in order to improve the system:

- Collect and publish much more comprehensive data
- Give all applicants the right to an independent advocate to navigate the complex and bureaucratic system
- Applicants with a progressive or non-improving condition should not be continually reassessed for their eligibility
- All assessments must demonstrably collect and consider evidence from healthcare professionals with expertise in that condition
- Clinical Commissioning Groups must be fully accountable for poor practice

16 December 2014