Written evidence submitted by Parkinson’s UK (CSR0041)

About Parkinson’s UK

1. Every hour, someone in the UK is told they have Parkinson's - a brain condition that turns lives upside down, leaving a future full of uncertainty.

2. Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

3. We want everyone to receive the best health and social care, so we bring professionals together to drive improvements that enable people to live life to the full.

4. Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

5. Together we can bring forward the day when no one fears Parkinson's.

Overview

6. Parkinson’s UK welcomes the Health Select Committee’s inquiry into the impact of the Comprehensive Spending Review (CSR) on health and social care. We would be pleased to provide further written or oral evidence.

7. Our key concerns are:
   a. The measures announced in the CSR fall far short of what is necessary to address the social care funding crisis
   b. The estimated investment in social care set out in the CSR document is not a credible prediction of what local authorities may actually raise from a social care precept
   c. Total additional funding for social care should be made available this year rather than by 2020 as it is urgently needed to plug the gaps that exist
   d. The Government intends to use additional funding within the Better Care Fund (BCF) to offset the disparities in revenue raised by local authorities that implement the two per cent social care precept

The distribution of funding for health and social care across the spending review period

8. We welcome the significant continued investment in the NHS, including a real terms increase of £10 billion per annum more in real terms by 2020-21 than in 2014-15\(^1\), and the confirmation that ‘£6 billion available by the first year of the Spending Review’ to fund the Five Year Forward View. However, Parkinson’s UK is extremely concerned that social care will have received a total investment of only £1.5billion from central government over the same period of time.

9. Research conducted by Sheffield Hallam University\(^2\) found that timely access to social care was found to have a preventative benefit, by stopping negative and costly


\(^2\) McDonnell, A et al (2014), ‘Putting people with Parkinson’s in control: exploring the impact of quality social care’
consequences, including the need for live-in or residential care and reductions in hospital admissions and GP visits.

10. Forthcoming research commissioned by Parkinson’s UK, which evaluates a Department of Health social care pilot project undertaken in Stoke between November 2010 – March 2014. The pilots emphasised a personalised, person-centred approach to social care for people with long-term neurological conditions, including Parkinson’s.

11. The project found that a more co-ordinated and accessible social work team that can meet demand, that has a clear understanding of complex neurological conditions, and is linked into a person’s wider professional network can enhance quality of life for people with Parkinson’s.

12. Given the importance of social care as a form of ‘preventative healthcare’, it is unacceptable for the Government to invest so heavily in healthcare over each year of the spending review period, while making only a fraction of this funding available to social care services in years to come. This amounts to a significant wasted opportunity to address the growing crisis in social care funding. We are therefore concerned that this will simply increase pressure on acute health services, as people with Parkinson’s are less likely to receive the support they need to maintain their independence and prevent, reduce or delay the likelihood of avoidable hospital admissions. We note, for example, that a National Audit Office report into services for people with neurological conditions found that neurological inpatient admissions stood at 463,510 in 2013-14 (the most recent data available)\(^3\)

Social care funding, including implications for quality and access to services, provider exit, funding mechanisms, increasing costs and the Care Act provisions

13. People with advanced Parkinson’s often benefit from social care support, to enable them to maintain independence, interact socially and play a fuller part in society. Unpaid carers of people with Parkinson’s can also benefit from this support, to help them maintain their independence and give them a break from their caring responsibilities.

14. Social care support is also vital in supporting family members who provide unpaid care to people with Parkinson’s and prevent them from developing long-term conditions and health issues of their own, as a result of their caring responsibilities. However the needs of carers are often overlooked too.

15. A carer of a person with Parkinson’s explains:

‘Carers predominantly think of the wellbeing of the person they care for, rather than their own situation. In my 33 years as a carer nobody asked me how I was myself or how I was coping. I managed - but there must be many carers out there who find out too late that their health (either physically or mentally) has become strained under the duress of caring.’

16. Despite the vital importance of social care as a form of ‘preventative healthcare’ for both people with Parkinson’s and their carers, funding available for this vital support has reduced significantly during the previous Parliament. For example, research

Sheffield Hallam University Centre for Health and Social Care Research, available at: [http://shura.shu.ac.uk/7965/](http://shura.shu.ac.uk/7965/)

published by Age UK⁴ in January 2015 showed that national social care spending for older people has fallen by over £1billion (14%) since 2010/11. The research also found that as of January 2015, only 9.1% of older people (849,280) receive any support. Although this represents a reduction of over 40% since 2005/6, the number of people aged 65 and over has increased by 15% (1,254,879) during the same period.

17. Although the Coalition Government introduced an additional £7.2 billion for social care between 2011/12 and 2014/15, the Association of Directors of Adult Social Services (ADASS)⁵ warned that ‘the £7.2 billion has not proved to be the funding solution for adult social care to anywhere near the extent that the Government argues it has’ and that adult social care departments have been forced ‘to make budget savings amounting to 26 per cent over the last four years, the equivalent of £3.53 billion. This is the amount departments have had to save to keep expenditure broadly where it is’.

18. Given the need for significant additional investment in social care in order to address issues of rationing, Parkinson’s UK is extremely disappointed at the CSR announcements of:
   a. a two percent council tax precept which local authorities may choose to levy, in order to increase the availability of social care funding locally
   b. limited additional funding for the BCF.

19. We outline our concerns related to the BCF in more detail in response to question three.

20. The Department of Health estimates that if all local authorities implemented the social care precept ‘to its maximum effect’ it could help raise nearly £2 billion a year by 2019-20⁶. There is a very small likelihood that all local authorities will implement the precept for each of the four years of the CSR period. For this reason, Parkinson’s UK does not believe the estimated investment in social care set out in the CSR document to be a credible prediction. We are also concerned that the total additional funding would therefore only arrive by 2020, instead of being made available this year, when it is urgently needed.

21. Parkinson’s UK recommends: The Department for Health clarifies its rationale for predicting that all local authorities will implement the two percent social care precept in all years of the spending review, and produces a more realistic assessment for the amount of money that could be raised by the CSR provisions.

Impact of the spending review on the integration of health and social care

22. Parkinson’s UK welcomes the recent announcement of two new national conditions for the BCF in 2016/17 which require local areas to fund NHS commissioned out-of-hospital services and to ‘develop a clear, focused action plan for managing delayed transfers of care’ including locally agreed targets⁷.

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23. Avoidable delayed transfers of care are a particular problem for people with Parkinson’s, who are often forced to remain in hospital for longer than necessary because of medication errors, which can make a person’s condition deteriorate. When people with Parkinson’s are unable to get their medication on time, symptoms can rapidly worsen including freezing, tremor, muscle rigidity, pain, fatigue, difficulty swallowing, loss of continence, sleep problems and anxiety.

24. Graham Price, 75, started caring for his wife Maureen after she was diagnosed with Parkinson’s six years ago. Although the Parkinson’s was progressing, each day Maureen would walk around a mile through her local park. But when Maureen collapsed and was admitted to Birmingham City hospital, things took a turn for the worse. Like all people living with the condition, Maureen relied on her medication to control her Parkinson’s symptoms. She took this six times-a-day, at specific times to stay as well as possible. But during her stay in hospital Graham noticed that medication was being given late. There was a notice above Maureen’s bed noting the correct medication times, but the nurses didn’t adhere to this, even after Graham had pointed it out to them. Maureen went on to develop problems swallowing, she became rigid, which meant she wasn’t able to have physiotherapy to help keep her moving.

25. Sadly, Maureen has not fully recovered from her 11 week experience in hospital. She can no longer stand or walk and now lives in a care home. Graham shared his story as he didn’t want this to happen to anyone else and he feels that if there had been a better understanding of Parkinson’s and the importance of Maureen getting her medication on time then she would have a much better quality of life now.

26. Many people with Parkinson’s who are admitted to hospital experience serious disruption to their medication regime. This frequently leads to a deterioration of their condition and more time spent in hospital, exacerbating the pressures on already stretched resources. In 2012/13 in England more than £20 million was wasted on 128,513 excess bed days for people with Parkinson’s as they stayed in hospital longer than they should, in part due to medication errors.

27. Although we recognise that the BCF has seen an increase in funding of around £1.5billion as a result of the CSR, we note that increased funding for the BCF will only be available ‘from 2017’ and will only reach £1.5billion by 2019-20, to be included in an improved BCF, according to the CSR document.

28. Given the critical shortage of funding at the present time, it is therefore extremely concerning that the funding will be phased in over the four years of the spending review period, in order to provide a real-terms increase only by 2020. Staggering funding in this way could reduce the effectiveness of the BCF as a method of focusing local commissioners on reducing delayed transfers of care and commissioning out-of-hospital services, and may have a significant, harmful impact on the provision of local authority funded care and the continued existence of the local social care marketplace.

29. **Parkinson’s UK recommends:** The Department of Health and HM Treasury front-loads the limited additional investment from central government into the social care system, in order to reduce the growing social care funding crisis

30. Furthermore, we are disappointed that the Government intends to use additional funding within the BCF to offset the disparities in revenue raised by local authorities that implement the two per cent social care precept. We believe that the BCF funding should be ring-fenced, to ensure that it is used by local authorities for the purposes of integrating health and social care and reducing delayed transfers of care. The Government should therefore find additional sources of funding to offset the social care precept, or reconsider the mechanism for funding social care so as to avoid disparities in the first place.

31. **Parkinson's UK recommends:** The Government ring-fences the BCF so that this funding is not used to offset the poor design of the social care precept.

**Quality and access in health and social care**

32. We are concerned that giving local authorities the option to raise council tax by the two percent precept undermines the ambition of the Care Act, which seeks to uniformalise social care provision across England. Local authorities that choose to implement the precept will receive different amounts, and many local authorities will not choose to introduce the precept at all.

33. Although it is too early to fully understand the impact of the CSR on the quality and provision of health and social care services for people with Parkinson's, we are extremely concerned that the estimated £2billion made available as a result of the CSR will fall short of what is necessary to address the critical social care funding shortage. In turn, this is likely to increase the rationing of social care provision, and could mean that people with Parkinson's are unable to receive social care before they reach crisis point.

**Conclusion**

34. Parkinson’s UK is concerned that the announcements made in the CSR amount to a failure to address the growing crisis in social care funding, and will lead to further rationing of social care for people with Parkinson's, and a reduction in their independence and quality of life as a result.

35. In particular we recommend:
   a. The Department of Health clarifies its rationale for predicting that all local authorities will implement the two percent social care precept in all years of the spending review, and produces a more realistic assessment for the amount of money that could be raised by the CSR provisions.
   b. The Department of Health and HM Treasury front-loads the limited additional investment from central government into the social care system, in order to reduce the growing social care funding crisis
   c. The Government ring-fences the BCF so that this funding is not used to offset the poor design of the social care precept.

*22 January 2016*

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