

Parkinson's UK submission to the Health and Social Care Committee inquiry – Social care

Summary

- The social care system is chronically underfunded. This leaves many people with Parkinson's experiencing poor quality care or denied access to services.
- Additional funding from government is required to sustain care and support in the future in order to meet the needs of an ageing population.
- The Department of Health should work across government to make an economic case for investment in social care. There is a case for the White Paper on social care to be sponsored across government.
- The Dilnot Commission provides a welcome framework on how to make the system more equitable, particularly for those in residential care. We urge government to implement its recommendations and that of the Law Commission, and legislate swiftly in 2012 for a fairer system of care.
- A major concern for people with Parkinson's is inequality in accessing and receiving care and support. It is also important the White Paper addresses charging concerns.
- People with Parkinson's have expressed general dissatisfaction with local authority funding decisions and strong support for entitlements and decisions to be taken at a national level by an independent national body.
- We are disappointed that government has not taken the opportunity to put social care on the same policy and strategic footing as health and public health. There is lack of "carrots and sticks" to make the necessary improvements nationally and locally in terms of delivery and quality in social care.
- For people with long term conditions, such as Parkinson's, integrated care planning, provision and review is essential. We co-sponsor a project called Neurological Commissioning Support that can provide advice to commissioners on how this can be achieved.

Full response

1. It is estimated that 120,000 people in the UK have Parkinson's. Parkinson's is a progressive, neurological disorder, with no known cure. Parkinson's affects people from all social and ethnic backgrounds and age groups. The average age of onset of Parkinson's is between 50-60 years of age, though one in seven will be diagnosed before the age of 50 and one in twenty will be diagnosed before the age of 40
2. Appropriate social care provision is crucial to quality of life for people affected by Parkinson's. As the condition progresses and there is a greater impact on daily living activities, this can result in an increased dependency for support and care, either informally or through formal care services.

The Government's plans for funding social care

3. Social care funding has failed to keep pace with demography. Since 2004 NHS spend has risen by £25 billion. Age UK has estimated that spending on older people's social care in that same period rose by just £43 million, 0.1% in real terms.¹ The Department of Health's own figures show that demand for social care is outstripping expenditure by 9%.²
4. The chronic underfunding manifests itself in many ways. For example, there is clear evidence of unmet need amongst people with Parkinson's. A survey of Parkinson's UK members³ found, one in five (19%) of people with Parkinson's who said they needed personal care and support were not receiving any help. Only 11% of carers were receiving support from social services, a fall from 16% in our 1997 survey.
5. The Comprehensive Spending Review announced additional £2 billion in funding for social care each year from 2011-2015. However this is against a picture of 27% cuts to council budgets in the same period. A clear pattern of cuts is emerging:
 - A total cut to adult social care budgets of £1 billion in 2011-12.⁴
 - Net expenditure on older people's social care to fall by 8.4% next year.⁵
 - A Care & Support Alliance survey showed that services to 24% of disabled adults had already been cut in early 2011, even though their needs were the same or had increased.⁶
 - The scaling back of eligibility for services and a number of court challenges.⁷
6. The evidence is clear that additional funding from government is required to sustain care and support in the future in order to meet the needs of an ageing population.
7. This debate is separate to the debate over the funding needed to implement the Dilnot Commission's proposals. Indeed this was recognised by the Commission: "*In addition to*

¹ Age UK Care in Crisis (2011). <http://www.ageuk.org.uk/latest-press/care-in-crisis-the-human-cost/>

² *Personal Social Services Expenditure and Unit Costs: England 2009 -10 – Final Council Data* (2010) The Information Centre, Department of Health

³ Parkinson's UK. *Life with Parkinson's today – room for improvement*. (2008)

www.parkinsons.org.uk/about-us/results-of-the-members-survey.aspx

⁴ *ADASS Budget Survey 2011* (2011)

⁵ Age UK survey (2011) www.ageuk.org.uk/latest-press/spending-on-older-peoples-care-to-be-cut-by-84

⁶ *Submission to the Dilnot Commission Call for Evidence* (2011) Care and Support Alliance. See:

www.parkinsons.org.uk/about_us/news/news_items/all_news/survey_care_cuts.aspx

⁷ For example, Care Quality Commission. *The State of Health Care and Adult Social Care in England*. (2010) Figure 8, page 35. www.cqc.org.uk/stateofcare.cfm

funding for the new capped cost offer, there will also need to be additional public funding for the means-tested system."

8. Dilnot did not put a figure on the level of funding needed for the current system, but was "concerned that not all the additional money from government to councils has made its way to social care." Parkinson's UK strongly supports Dilnot's call for resources made available locally for adult social care each year to be transparent and subject to national oversight.
9. When we surveyed people with Parkinson's for the "Big Care Debate" in 2009 we found that there was general dissatisfaction with local authority funding decisions. Just 12% of people with Parkinson's believed that decisions about how much money should be spent on care should be made by local government, with 65% favouring an independent national body.
10. Total social care spend is a product of 152 council decisions. We support the King's Fund analysis that this has been detrimental for social care and that government should adopt a single strategic assessment of the funding needs of the NHS and social care.⁸
11. Social care is often seen as a burden on the state, when it should be seen as an investment. It could generate significant savings, for example, by ensuring that people with long term conditions and carers do not have to give up work, and by reducing the need for more costly health interventions.⁹
12. The Department of Health should do more to ensure cross government support from the Treasury and Department for Business, Innovation and Skills on the benefits that could arise from investment. There is a case for the White Paper on social care to be sponsored across government.

Recommendations of Dilnot and Law Commissions

13. Parkinson's UK strongly supports the contributions from the Dilnot Commission and the Law Commission. Implementation could lead to a more consistent, fairly funded care system that is easy to understand and ensures people with Parkinson's do not bear the financial burden of their condition. While people affected by Parkinson's have always supported a free at the point of delivery national social care system, we recognise that this is politically unpalatable in the current funding environment.
14. We particularly welcome Dilnot's rejection of a voluntary insurance funding model which could lead to discrimination for those with pre-existing conditions such as Parkinson's, who frequently report difficulties obtaining insurance.
15. In particular, Parkinson's UK supports the following recommendations:
 - A capping of lifetime costs for care and a more generous means test in residential care.
 - Recognition that younger people cannot afford to contribute as much for their care, through a tiered approach to capping.
 - A new strategy for awareness, advice and information around care and support.

⁸ Social care funding and the NHS, an impending crisis? (2011)
http://www.kingsfund.org.uk/publications/social_care_funding.html

⁹ The case for social care reform – the wider economic and social benefits (2010)
www.hsmc.bham.ac.uk/news/news/2010/2/social-carereform.shtml

- The introduction of a national system of eligibility and assessment.
16. However, a Dilnot system will need safeguards. This includes how a notional metering system would work (ie the period when the person's own expenditure on care counts towards the cap). Councils will be tempted to undervalue this package so it takes longer to reach the point at which they will step in and fund the care.
 17. The metering phase need to be "carer sighted", ie the more care the unpaid carer provides, the slower the progress towards the cap. If assessed needs are fulfilled by family members then the 'meter' should start running on the £35,000 cap, otherwise this would be a disincentive for families to care.
 18. We believe improvements could be made in respect of Dilnot's homecare proposals. Currently, those with some income can be left with as little as £160.08 per week to live on while savings from £14,250 onwards are taken into account. We would like to see a raised means-test threshold for homecare, while property assets must continue to be disregarded. This would remove perverse incentives for people to move into paid for residential care early, not build up any savings or to decline costly homecare packages.
 19. Parkinson's UK does not support Dilnot's suggestion of setting criteria at substantial needs nationally as an interim move. It runs counter to the preventative agenda and it means the metering system will only start when people require substantial care, meaning a person's own expenditure prior to this will not count. This will be particularly unfair for people with a gradually progressive condition, like Parkinson's.
 20. We welcome Dilnot's rejection of incorporating disability benefits into the social care funding system. However the Dilnot system will mean self funders in residential care who become "state funded" once the cap is reached will lose their Attendance Allowance (or DLA) at this point. These savings must go back into social care, and not (as happened in Scotland upon the introduction of free personal and nursing care) back into the DWP budget.
 21. In principle we object a system that will not cover accommodation costs in residential care. But if implemented then such costs should be capped to a maximum of £7,000 so that costs are affordable. In Scotland accommodation costs were not capped when the free personal and nursing care policy was introduced, so individuals can end up paying over £400 a week in hotel costs.
 22. We reject Dilnot's suggestion that NHS Continuing Care funded residents should pay their accommodation costs. This erodes the principle that NHS care should be free at the point of delivery.

The scale and implications of existing variation in access to and charges for social care in England

23. The postcode lottery of care is a major concern for people with Parkinson's from our surveys and the All Party Parliamentary Group for Parkinson's Disease Inquiry Report.¹⁰ We are running a national campaign – Fair Care – to address the inequalities that people with Parkinson's face.¹¹

¹⁰ Please mind the gap: Parkinson's disease services today (2009). www.parkinsons.org.uk/about_us/policy_and_campaigns/1/parliaments_and_assemblies/appg/appg_report.aspx

¹¹ See our campaigns pages www.parkinsons.org.uk/faircare.

24. A national framework or national standards would create a fairer system and benefit disabled and older people and carers as they would have more certainty about their entitlement and it would reduce the inequity across the country.
25. Reforms must encompass concerns about charging. Parkinson's UK is a member of the Coalition on Charging which is seeking a fairer charging system. A recent sample of 15 councils¹² revealed massive increases in costs for hourly and weekly homecare charges. There is evidence that charges lead to people avoiding engagement with social care until crisis point.
26. There should be flexibility for councils not to charge for services, and capping of maximum charges councils are able to make while ensuring there is a more generous disregard so that people are not left in poverty after deductions are made. We note that Wales has implemented a package including maximum £50 a week for community care charges to address these concerns.¹³
27. People with Parkinson's also want a national body who can hold local authorities to account in order to ensure that people in need are not being denied care. But localism has removed any national oversight of commissioner (council) performance. Instead councils self-report on their performance against a new adult social care outcomes framework.
28. We are concerned that there are no levers or incentives to drive up quality of commissioning and fear that this will lead to more inequity of services. It is not enough for the Department of Health to plead tough regulation of providers and hope for the best on commissioners. It is unclear how effective national HealthWatch will be while NICE Quality Standards will only be good practice.
29. We are calling for social care to gain some strategic equivalence with health and public health. For example through:
 - Duties on commissioners to secure continuous improvement in social care;
 - A national body (like NHS Commissioning Board and Public Health England) with oversight of performance in the sector;
 - Quality Standards and outcomes frameworks that act as levers and attract premiums and rewards on progress towards specific outcomes; and
 - a focus on inequalities and national datasets to allow comparison between areas
30. We are also concerned that the funding and delivery proposals for local HealthWatch could leave it a weak vehicle for local scrutiny and calling councils to account. The Future Forum recommended a duty on councils to have regard to HealthWatch investigations¹⁴ but it appears this will not be implemented. There is little detail on the Department's promise to look at a citizen's right to challenge poor quality services and lack of choice.¹⁵

The practical and policy implications of personalisation

¹² Homecare service charges. (2011) <http://www.disabilityalliance.org/cohomecare.htm>

¹³ See Welsh Assembly Government press release (2011) <http://wales.gov.uk/newsroom/healthandsocialcare/2011/110325socservices/?lang=en>

¹⁴ See Patient Involvement and Public Accountability: A report from the NHS Future Forum. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_127544.pdf

¹⁵ See Government response to Future Forum report. Para 5.38 http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_127544.pdf

31. We welcome the government's vision to extend availability of personal budgets, alongside the Law Commission's proposals for a duty on councils to stimulate the market for social care, and legislate for direct payments to cover residential care.
32. However the rhetoric of personalisation is yet to match the reality on the ground. In 2010 we ran a project to look at people's experiences of personalisation.¹⁶ People with Parkinson's reported a lack of good quality information, uncertainty about eligibility, variation in the support needed to help make choices (such as advocacy), assessments that led to very little help and a lack of services to choose from.
33. There was also wariness with the bureaucracy involved in managing payments. Not all people with Parkinson's or carers wish to use eg. direct payments, and it is important that people are given genuine choice, including the ability to use traditional services.
34. Since that study pressure on social care budgets has led to personalisation being used as a way to reduce costs of care.¹⁷ This is not helped by a system for allocating resources which is opaque and variable depending on where you live.
35. There remain concerns about the conduct and skills of directly employed care workers and we believe there is a need for greater oversight of this workforce. There is evidence that options for background checks are not being used by some people in receipt of direct payments.¹⁸
36. Finally there needs to be good information on the "marketplace" so the "consumer" can exercise more choice. We are concerned that the information provided by the regulator, the Care Quality Commission, can be out of date by many months or years and registration with CQC is nothing more now than a license to practice.

Economic regulation of the social care system

37. The developments at Southern Cross also bolster our case for government oversight of commissioning behaviour in both residential and domiciliary care markets. Many councils are retendering domiciliary care contracts with the aim of cutting numbers of providers and costs. The pattern emerging is of bigger national companies undercutting smaller local providers. We therefore support economic regulation provided that the focus of competition is on quality.

Integration between health and social care services

38. While Dilnot does not propose the end of a means tested social care system, a reduction in the catastrophic costs of social care could help reduce the unfairness experienced by people deemed in need of social care rather than health care.
39. However the gap between health and social care will remain and it is essential that councils and the NHS use every opportunity to build a care service based around the person. This is particularly important for someone with a long term condition such as Parkinson's where integrated care planning and review is essential.

¹⁶ Parkinsons UK. *Choice, control and personalised services – final report* (2010)

¹⁷ Radio 4 You and Yours, Charities in social care personal budgets warning (3 December 2010) www.bbc.co.uk/news/uk11909505

¹⁸ Skills for Care. *The Employment Aspects and Workforce Implications of direct payments* (2008)

40. Good commissioning of integrated services for people with Parkinson's can save up to £56 million, for example with investment in community and rehabilitative services.¹⁹ We co-sponsor the Neurological Commissioning Support project with the MS Society and Motor Neurone Disease Association.²⁰ This provides guidance to commissioners on how to commission for quality neurological services including across social care. We have also been involved in research on care pathways, including social care, for people with neurological conditions²¹ which found rehabilitation and day opportunities are important priorities.
41. The last decade have seen integrated service projects that prove there can be cost savings and better outcomes for people. However progress is still piecemeal rather than widespread.²²
42. We welcome the focus of integration in the new health reforms. However, the lack of levers and scale of cuts in social care mean there remain questions on how to really make integration happen. In an increasingly crowded health landscape we are concerned that social care will remain a poor relation.

¹⁹ Moving and shaping, A guide to commissioning integrated services for people with Parkinson's Disease (2006) <http://www.scie-socialcareonline.org.uk/profile.asp?guid=340cc60b-10ab-4c84-8077-0cfcde59b818>

²⁰ Please see <http://www.csupport.org.uk/> for more details

²¹ Integrated services for people with long term neurological conditions (2010) http://www.sdo.nihr.ac.uk/files/project/SDO_FR_08-1610-124_V01.pdf

²² For example, Total Place pilot www.dorsetforyou.com/media.jsp?mediaid=143386&filetype=pdf