

Parkinson's UK policy statement

Funding and delivering long-term care

"I was told that when my elderly mother came home from hospital that they could not provide two careworkers to assist in getting her up and putting her to bed ... one carer could not manage her on their own, therefore she had to go into a home. We had no other choices offered to us (she had advanced Parkinson's). There should be a wider range of choice, not ultimatums."

"The big problem facing younger people with Parkinson's and their carers is that most are living in relative poverty through having to give up work at a young age. They aren't able to save for their pension, let alone their care needs."

"There are ongoing battles between services as to who pays for what and who is responsible for what! The needs of the person become lost to bureaucracy."

People with Parkinson's and their carers

What we believe

Parkinson's UK believes that everyone who needs long-term care should get appropriate high quality integrated support that is tailored to their individual needs. This should be delivered through consistent, fairly funded national care systems that are easy to understand and ensure people with long-term conditions and disabilities do not bear the financial burden for their condition.

We believe that a tax or national insurance funded model delivering national entitlements to social care is the fairest and most appropriate way to address the current postcode lottery in the system and bridge the divide with health. We do not support the incorporation of much valued disability benefits into the social care funding system. People with Parkinson's and their carers and families should also be provided with information about care options well in advance so they can make informed decisions.

Principles for funding and delivering care

We believe that systems for funding and delivering long-term care should meet certain principles. Our preference for a national tax or national insurance funded system is because we believe this model is most likely to meet these principles. Alternative models proposed may have merits, such as the potential to pay care costs through compulsory insurance or levies on an estate, significantly increasing the mean-test thresholds for local authority funded care or capping of a self-funder's social care costs, but are less satisfactory in terms of meeting these principles.

Funding

- Additional funding from governments is required to sustain care and support in the future in order to meet the needs of an ageing population.
- There should be national systems in place that guarantee everyone can get the support they need, wherever they live, regardless of ability to pay.
- The systems should ensure that people with long-term conditions and disabilities are not penalised.

- Self-funders should not be penalised with higher care costs.
- The funding systems must be easy to understand and access – with clear information about how people are expected to contribute and how much.
- Disincentives for people to work and save when they are well should be minimised.
- Those without any means to fund or provide their own care should be enabled to access appropriate support.
- If people are paying for their own care they must have access to appropriate advice and information to help them access the services they need.
- Attendance Allowance and other disability benefits should be available and easily accessible as a popular, effective and flexible means of meeting an individual's disability related costs and not be taken into account during assessments to pay for care costs.
- Accommodation costs should be taken into consideration by the funding systems in place.
- Although we pragmatically support the capped cost model for people who self-fund their care, as an alternative to a “do nothing” option, we believe that it should be set at a level that enables people to avoid catastrophic care costs. Care costs have been capped in Wales since 2011. See below section on funding for more detail.
- Local authorities must receive sufficient funding to ensure they are able to fulfil their legal obligations under any relevant legislation and prevent the rationing of care.

Delivering care

- Social care must be clear and easy to understand, access and use, free of stigma, with a national system of assessment and eligibility in each country.
- Local authorities and health bodies must be required to work together to deliver joined-up integrated care and support for people with Parkinson's.
- Local authorities should not take benefits into account as income when assessing people for care.
- Care planning for people with Parkinson's should follow an ‘anticipatory approach’ that assesses long-term needs and provides individualised support that increases in-step with a person's growing care needs, recognising that Parkinson's is a long-term fluctuating and progressive condition.
- The contribution of carers should be properly recognised, with appropriate support, including respite, provided to those who need it and this should be reflected in legislation.
- Services must be flexible and built around the needs of the individual. They must have the ability to choose and control the type of support provided and how it is delivered.
- Encouraging preventative measures should be central to any system and proper account must be taken of the real cost of not providing services.
- Information about what support may be available and how to get it must be accessible to all, including those funding their own care, with advocacy and brokerage for those that need these services.
- Assessments should explore ways to ensure independence and include self-management where appropriate.
- Where providing care at home is in the best interests of the individual, this option should be available. People should not be forced into residential care purely for cost reasons.
- National standards for commissioners and providers must be in place to ensure high quality care services. Performance against these standards must be monitored, regulated and enforced where people are experiencing poor levels of care.

- People must be safeguarded from abuse and neglect, and have their dignity protected, with clear complaints and appeals procedures in place.
- Staff in health and social care settings must have information and learning opportunities about the condition through the UK Parkinson's Excellence Network so they understand how they can provide high quality services that are appropriate for people with Parkinson's.
- There should be a consistent high-quality approach to the adult social care workforce, to ensure they have an equal status to the healthcare workforce and meet standards of care. This has been addressed to some extent in Wales and Scotland via the Regulation and Inspection of Social Care (Wales) Act 2016 and the introduction of workforce registration in Scotland since 2009.

Why we believe this

Parkinson's can have a big impact on all aspects of daily living as the condition progresses. Many people with Parkinson's become increasingly reliant on care and support in order to maintain their quality of life. A significant number of people with Parkinson's will need a comprehensive package of care at home, or in long-term residential care. However, people with Parkinson's face a number of barriers to accessing good quality long-term care.

Funding

As care arranged by social services is means-tested, the outcome of any decision can have significant financial consequences for the person with Parkinson's and their family. If a person is just over the means-testing limit, they may face a lifetime of paying for care and may have to sell their home to enter residential care. This can seem extremely unfair. The rapid increases in charges for social care, and differences in charging policies also adds to the complexity and variation in the system.

Capped care cost models, if introduced, should be set at a level a level that provides meaningful for people with Parkinson's and their families to avoid catastrophic costs. For example, the Commission on Funding Care and Support's report concluded that a cap '*should be between £25,000 and £50,000*' and noted that £35,000 was an '*appropriate and fair figure*' arguing that '*a cap outside of this range would not meet our criteria of fairness or sustainability*'¹ we would support the introduction of a cap on care costs at the lower end of this range.

We also believe that models for capping social care should apply retroactively, to prevent people who have contributed significant lifetime costs from losing out from an arbitrary start date.

Paying for long term care in Wales

In 2011 Welsh Government introduced a limit on the amount local authorities can charge a person for the care they receive at home or within the community. The limit in place is currently £80 per week.

In 2016 Welsh Government made a commitment to increase the amount of capital a person can keep without having to use this to pay for their residential care. Capital includes savings, investments and the value of property you own, unless a partner, ex-partner or dependant relative will remain living in it. The commitment is to uplift the amount from £24,000 to

¹ Commission on Funding Care and Support, *Fairer Care Funding* (2011)

£50,000, introduced in a staged approach. The amount was raised to £40,000 from April 2018.

To decide how much to charge, local authorities must carry out a financial assessment. You can ask for a review of any charge made by your local authority that you think is incorrect.

Non-residential care in Wales

People may have to pay up to a maximum of £80 a week if:

- they have a high level of disposable income
- they have savings and investments over £24,000, not including the value of your home

In deciding charges for non-residential care, local authorities must allow people to keep a set amount to help people meet daily living costs.

Residential care in Wales

If someone has capital over £40,000 they may have to pay the full cost of residential care. If capital is at or below this limit, the local authority will help pay for residential care. How much people pay towards this care will be calculated from eligible income, such as pensions or welfare benefits. Local authorities must ensure people are left with at least £28.50 a week to spend on personal items.

Paying for long-term care in Scotland

In Scotland, some social care is provided free of charge. People aged over 65 currently receive free personal and nursing care, and those under 65 receive free nursing care.

From April 2019, people under 65 will also qualify for free personal care. Personal care has a strict definition in law, and social care that falls outside the following definition is chargeable:

- **Personal hygiene** - Bathing, showering, hair washing, shaving, oral hygiene, nail care
- **Continence management** - Toileting, catheter/stoma care, skin care, incontinence laundry, bed changing
- **Food and diet** - Assistance with the preparation of food and assistance with the fulfilment of special dietary needs
- **Problems with immobility** - Dealing with the consequences of being immobile or substantially immobile
- **Counselling and support** - Behaviour management, psychological support, reminding devices
- **Simple treatments** - Assistance with medication (including eye drops), application of creams and lotions, simple dressings, oxygen therapy
- **Personal assistance** - Assistance with dressing, surgical appliances, prostheses, mechanical and manual aids. Assistance to get up and go to bed. Transfers including the use of a hoist

People may also be charged for these services if they do not meet eligibility criteria. If someone is admitted to a care home and is a self-funder, the care home will receive a fixed payment from the local authority (in 2018-19 it is £114 a week for personal care and £79 for nursing care); however, self-funders must pay their accommodation costs. In 2015/16 the average weekly charge for self-funding long stay older residents with nursing care was £814 per week.

Information and choice

In England local authorities are required to provide information about accessing services and support under the Care Act. In Wales and Scotland, there are similar requirements under

legislation. Yet it is unclear how comprehensive this information is. For those organising and paying for their own care it is particularly difficult to get advice and information.

Despite encouragement for people to exercise choice, including equipping them with their own budgets, there may be little real choice of services in a locality, especially for younger people with Parkinson's. Where people are given their own budgets or payments, these may not meet the level needed to buy a service of their choice.

Rationing

The current system is driven by local authority budgets and services rather than meeting the needs of users. The Care Act's standardised eligibility criteria for local authorities in England, are pegged to the equivalent of "substantial" care needs under the previous criteria. In Wales people only become eligible for care and support if their needs 'can and can only' be met by social services intervention. This has led to people with Parkinson's being unable to get the support they need or having it withdrawn. In some cases, this puts people in crisis, jeopardising their health and incurring increased costs in the longer-term.

To benefit people with Parkinson's, including those who may be diagnosed at a younger age we believe that the eligibility criteria must be set at a lower level. This will ensure that people in the earlier stages of the condition to have their needs met, and not suffer isolation because of their social care needs being unmet.

Joining up health and social care

There is a lack of joined up working between health and social care, with people repeating their needs to many different people. We believe this must be tackled to ensure more effective care is delivered that meets the specific needs of an individual.

Welsh Government recently published 'A Healthier Wales'² which sets out Welsh Governments long-term vision for achieving a 'whole system approach to health and social care over the next 10 years with the expectation that change will be at pace.

The lack of integration in England and Wales means health and social care budgets can be confusing where the boundary between health and social care lies. This is most apparent with NHS continuing healthcare in England.³ People say that their long-term care needs are ignored – preventative measures and early interventions are given a low priority in most areas. Simple things like aids and adaptations that can provide cost-effective "low level" support are subject to long waits.

The Better Care Fund in England has been championed as a model of integrating health and social care services locally. However, the focus on reducing emergency admissions to hospitals⁴ is not a particularly useful metric for service integration. The Fund therefore requires a more appropriate series of outcome measures, if it is to be truly effective.

Quality

Despite regulation and assessment of services, there remain concerns over the quality of care services locally and whether information on services can be trusted to deliver high quality care for people with Parkinson's.

² Welsh Government *A Healthier Wales* (2018) <https://gov.wales/docs/dhss/publications/180608healthier-wales-mainen.pdf>

³ Please see our policy position statement on NHS continuing healthcare (add date)

⁴ National Audit Office, *Planning for the Better Care fund* (2014), available at: <http://www.nao.org.uk/wp-content/uploads/2014/11/Planning-for-the-better-care-fund-summary.pdf>

There are concerns that the way services are commissioned can be rigid and inflexible, leaving people feeling rushed and neglected. The shortfall in funding exacerbates low pay in the workforce, which suffers from high turnover and this damages continuity of care. People with Parkinson's say that many staff working in care settings have insufficient understanding of the condition.

What's the evidence?

Research findings

There is clear evidence of unmet need around social care among people with Parkinson's. Research we commissioned by Sheffield Hallam University and published in 2014 examined the impact of quality social care for people with Parkinson's. It found that people with the condition and their carers were often unaware of social care and how to access it until they were in a crisis situation and needed immediate help. The report recommended an 'anticipatory approach' to social care planning which increases in-step with a person's growing care needs.⁵

These findings were confirmed in 2016 with our 'Caring about Parkinson's' report⁶ which found that:

- Over half (51%) of respondents with Parkinson's and 76% of carers who answered the question "have you ever been offered an assessment of your own needs?" had never received an assessment.
- 74% of respondents with Parkinson's and 59% of carers were unaware of their local authority's social care information service and many people with Parkinson's and carers did not know how to request a social care assessment.
- Around a third of Parkinson's local advisers that responded to the survey disagreed that "assessments in my area have been conducted with a good understanding of Parkinson's" or asked about how a person's condition fluctuates.
- No carer in our survey reported receiving access to preventative support, despite Care Act guidance which emphasises the value of this support for carers.
- Of the 82 respondents who revealed the outcome of their social care assessment, almost a third were denied access to support because they were above the earnings threshold and a quarter gained access to additional support.
- 63% of local authorities who responded to Freedom of Information requests were unable to provide any of the requested information. In the majority of cases, this was because the local authority did not collect data by condition.
- Around 10% of the Parkinson's population identified across the 21 local authorities that did collect this data have seen reductions in their social care support, upon reassessment.

Research we published in July 2017 undertaken by Sheffield Hallam University⁷ outlined the cost of living with Parkinson's. This research showed that a UK household with someone with Parkinson's is £16,582 out of pocket each year. Of this £3,622 were social care costs such as adaptations to the home, equipment to enable people to stay independent and assistance with daily tasks such as cleaning and shopping.

⁵ McDonnell, A et al (2014), 'Putting people with Parkinson's in control: exploring the impact of quality social care' Sheffield Hallam University Centre for Health and Social Care Research, available at:

https://www.parkinsons.org.uk/sites/default/files/sheffieldhallam_socialcarereport2014.pdf

⁶ Parkinson's UK, Caring about Parkinson's, 2016, available at: https://s3-eu-west-1.amazonaws.com/puk-live-1-d8-ie/2017-09/care_act_experience_report.pdf

⁷ Cost of Parkinson's: Parkinson's UK, July 2017. <https://www.parkinsons.org.uk/news/whats-cost-living-parkinsons>

A Care and Support Alliance (of which we are a member) survey⁸ of nearly 4,000 people in England revealed that a widespread absence of care is making people unwell, unsafe and unfulfilled. It is also putting unnecessary pressure on the NHS and is pushing carers to breaking point. Key findings of the survey were:

- 1 in 5 have gone without meals due to a lack of care and support (20%).
- 1 in 4 have had to struggle with the basics (27%) such as getting washed and dressed in the morning.
- 1 in 5 shared they felt unsafe moving around their own home, and over a third can't leave the house (22% unsafe and 41% stuck at home).
- Over a third stated they felt lonely and isolated because of a lack of support (45%).
- Over a third have seen their health deteriorate as a result of not getting the care they need (43%).
- 1 in 6 have had to miss crucial medical appointments (18%).
- 1 in 4 have needed hospital treatment and 1 in 8 have been delayed leaving hospital because of not getting the care they need (29% hospital and 13% delayed transfer of care).
- Nearly half stated they rely on family and friends more (49%).

Rationing

Since 2010 there has been a £7billion reduction in adult social care funding. A recent survey⁹ by the Association for Directors of Adult Social Services (ADASS) of its members (in England) found that fewer older and disabled people with more complex care and support needs are getting less long-term care. 75% of directors reported that reducing the number of people in receipt of care is important or very important for them to achieve necessary savings.

The survey reflects the impact of additional funding for adult social care, which raised £1.5billion from the Improved Better Care Fund and £1.7billion from the social care precept¹⁰, to counter-balance savings of £700million in 2018/19, the adult social care element of overall council savings. The additional funding has avoided a far worse situation although the short-term funding provided has not given confidence in the ability to meet future legislative requirements – particularly with estimates of 1.2million people aged 65 and over with unmet needs¹¹.

Councils are spending an increasing proportion of their total budgets on social care: 34% in 2010/11 rising to almost 38% in 2018/19. Key drivers of rising pressures are increased and more complex needs of older and disabled people. Whilst more directors expect fewer people to be in receipt of state-funded care in the next two years, demographic changes are expected to cost an additional £448million (3% of budget) in 2018/19.

This is likely to have a significant impact on people with Parkinson's.

What Parkinson's UK is doing

We are working to ensure that people are aware of their rights to social care through our information resources, advisory services and local teams. We train professionals working with

⁸ Voices from the social care crisis: Care and Support Alliance, May 2018. <http://careandsupportalliance.com/bigsocialcaresurvey2018/>

⁹ Budget survey 2018: Directors of Adult Social Services, June 2018 <https://www.adass.org.uk/adass-budget-survey-2018>

¹⁰

Core spending power: final local government finance settlement 2018 to 2019, Supporting Information, February 2018 <https://www.gov.uk/government/publications/core-spending-power-final-local-government-finance-settlement-2018-to-2019>

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Briefing: Health and Care of Older People in England 2017, Age UK, February 2017 https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/care--support/the_health_and_care_of_older_people_in_england_2017.pdf

people with Parkinson's so they are better educated about the condition. We also campaign for fairer access to care services and improvements to the way social care is funded.

Acknowledgement

We are grateful for the advice and guidance of our Policy Panel in shaping this position paper on funding and delivering long-term care. The Policy Panel consists of people with experience of Parkinson's who meet on a regular basis to help guide the charity's position on a range of policy issues.

Further information

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