

Parkinson's UK policy statement Carers' support

"It is difficult to put into words the feeling of abandonment and loneliness I feel. Carers have enough to cope with without the constant battle to get some attention for their loved ones."

Carer giving evidence to the All-Party Parliamentary Group on Parkinson's.

What we believe

We believe that addressing the needs of unpaid carers, including those who provide support to people with Parkinson's, must be treated as a priority by local and national policy makers. This should be reflected through appropriate funding for carers' benefits and services, better information and advice, clear targets for improving support, and national outcome measures to monitor not only the performance of local authority and health services but also the personal wellbeing outcomes for individual carers.

Why we believe this

The support provided by partners, families and friends is essential to the wellbeing of people with Parkinson's. However, those providing care do not currently get the recognition and help they need and frequently suffer financially, socially and with poor health themselves as a consequence. This in turn impacts negatively on those they care for.

In the last decade we have welcomed a range of government interventions, including new legislation to improve carers' rights and the support available to carers.¹ However, evidence from successive Parkinson's UK members' surveys shows that these measures have not had a significant positive impact². We remain concerned that new reforms will not go far enough in providing the essential support that carers require. All governments across the UK have accepted the need to improve policies towards carers³, as demonstrated by recent changes to legislation, and we believe they should focus on the following priorities:

Recognition and resources

There is need for improved understanding of carers' needs. Also, professionals should be able to recognise carers as experts in the condition of the person they care for, and as partners in care. There are particular challenges for carers of people with Parkinson's, who often tend to be older and co-resident with a long history of caring. The challenges of caring for someone with a progressive condition are profound and there are often differences of opinion about needs and priorities for both carer and cared for.

¹ For example, see the *Care Act 2014 in England, the Carers(Scotland) Act 2016*

² Though anecdotal evidence from Wales has been more positive largely as a result of the Carers Strategies (Wales) Measure 2010 (now repealed) which placed a duty on health boards to plan strategically for carers, and it is too early to measure the impact of new legislation in Scotland.

³ For example, see Scottish Government and COSLA, *Caring Together, the Carers Strategy for Scotland* (2010), Department of Health, *Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own* (2008)

In recognition of their value to society, more should be done nationally and locally to ensure sufficient resources are allocated to, and spent on, meeting the needs of carers. The impact on carers' lives must be measured in a way that is personal and meaningful.

Information and advice

Universal information about rights to assessment as a carer, and to reassessment when circumstances change, is particularly important, as is information on benefits and financial advice. Information also needs to be targeted at seldom heard groups, including carers in rural areas and those from ethnic minority communities. People need to be supported to access this information.

Support and respite

There needs to be rapid and accurate assessment of carers' needs, with targets to increase awareness (particularly for the people who are in most need) and take-up of carers' assessments (also known as carers' support plans in Scotland) among carers of people with long-term neurological conditions. Assessments must consider the social, educational and employment activity that will help carers sustain independence, as well as any other personal wellbeing goals an individual carer may have, as was introduced in recent legislation in Wales and England. This should be underpinned by joined-up working between health and social services so each carer has a designated contact person and a joint assessment where appropriate. Support services must be appropriate to all areas of society, including carers from minority groups, older carers, those with health needs of their own and those living in rural areas. Carers should also be able to access this support before their needs reach crisis point.

Support should include consistent provision of breaks, planning for emergencies and help with end of life care. Every carer should have an opportunity to establish an emergency plan to ensure appropriate response and support in times of crisis when usual care arrangements break down. Those involved in the assessment of needs and provision of respite care must have an understanding of, or should seek insight into, Parkinson's and how the condition is managed as it progresses.

Carers' health needs addressed

There should be recognition of carers as an at-risk group for health problems who require preventive help and targeted support, including regular respite, annual health checks and flu jabs. The number of carers registered as such with their GP needs to increase, and health and social care professionals need to do more to recognise the needs of carers who themselves have poor health and disabilities. Carers' own health needs should be considered during their assessment (and as part of their support plan in Scotland and Wales) and appropriate services should be provided to address these, such as moving and handling courses, rapid provision of aids and adaptations or any other support required.

Financial support

Reform of Carer's Allowance is a particular priority as carers need a fair income and support if they wish to work or remain in work. A solution would be to raise the earnings limit for Carer's Allowance, as the limit prevents many carers from returning to work. Another would be to address the overlapping benefit rule that prevents those in receipt of a pension from receiving the allowance. There should be better information and advice about the benefits available and the right for carers to request flexible working from the Department for Work and Pensions,

Jobcentre Plus and other government agencies, as well as from employers themselves. There should be concerted action to encourage employers to support carers in the workplace.

What's the evidence?

In 2009 the All-Party Parliamentary Group on Parkinson's took evidence from people with the condition and their carers. The inquiry found that services for carers, such as respite breaks and emergency support, were lacking.⁴

Parkinson's UK commissioned a piece of research published in 2014, which examined the impact of good quality social care for people with Parkinson's. It found that the benefits of social care to people with Parkinson's had a positive impact on carers too, including on their health, wellbeing and relationships.⁵

In 2016, Parkinson's UK conducted research to examine how social care is working for people with Parkinson's and carers in England. It found that:

- no carer in our survey received access to preventative support, or respite care to help them manage their caring responsibilities
- 76% of carers who answered the question "have you ever been offered an assessment of your own needs?" had never received an assessment
- 59% of carers were unaware of their local authority's social care information service and many people with Parkinson's, as well as their carers, were unaware of how to request a social care assessment

What Parkinson's UK is doing

We are actively campaigning for improved carers' rights and services, and seek to provide comprehensive support for carers of people with Parkinson's through our information resources, advisory services and regional teams.

Acknowledgement

We are grateful for the advice and guidance of our Policy Panel in shaping this position paper on carers. 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

Please contact the Policy and Campaigns team. Tel: 020 7963 9307 or email: campaigns@parkinsons.org.uk

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⁴ All-Party Parliamentary Group for Parkinson's Disease. *Please mind the gap: Parkinson's disease services today* (2009).

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