



Parkinson's Disease Society response to Department of Health consultation on the extension and revision of the statutory guidance for charging for non-residential social services in relation to personal budgets

General comments

The PDS welcomes the opportunity to respond to the draft guidance on Fairer Contributions.

The PDS agrees that there is a need for new charging guidance, but is disappointed that the government has not taken the opportunity to undertake a wider review of charging policy guidance, especially in light of the forthcoming Green Paper on care and support.

The PDS would like to see the Department of Health undertake a detailed review of the impact of charging policies, which should examine the cost effectiveness of charging policies, taking into account the administrative and associated costs in establishing, advertising and operating a charging policy and the long-term impact on health and social care – people with Parkinson's tell us that they defer seeking support because of charges and this can result in unnecessary demands on the NHS in the long-term.

1. Do you agree that applying the same percentage to all personal budgets is a reasonable basis for calculating a contribution?

The PDS is greatly concerned that the guidance is effectively encouraging councils to end the provision of free services, in particular the wording of paragraph 19 of the consultation document, which states that those councils that provide some free services “will need to consider if they wish to continue doing this in exactly the same way.”

Councils that currently provide some services for free or at reduced costs should not be pressured to change their policies. Those currently receiving free services would be particularly hard hit by this change to the guidance.

Low-level early intervention can be a cost-effective means of enabling people with disabilities and their families to manage in the long-term and encouraging preventative measures should be central to any system of care and support. The Department of Health should be taking the lead on encouraging the use of preventative interventions, particularly where these are cost effective in the long-term. These might include measures to prevent falls, physiotherapy, respite care or carers' services that can help prevent carers from developing health problems of their own.

Further work is needed to establish the most effective means of ensuring that prevention is embodied at the heart of a social care system, but might include

identifying interventions that are cost-neutral or of cost-benefit in the long-term and providing these services free of charge. We would like the Department to explore the benefits of providing certain preventative services for free, with a view to producing good practice guidance on these types of services.

2. Do you think that the measures proposed appear equitable both for service users who receive existing services and for those receiving personal budgets

Poor understanding of Parkinson's by professionals can lead to the Disability Related Expenditure (DRE) costs not being properly taken into account. The PDS would like to see clearer guidance to support local authorities in making and communicating DRE assessments to help ensure that DRE assessments are calculated fairly and based on the individual's actual living costs.

3. Do you think that the guidance sufficiently underlines councils' responsibilities to ensure that policy changes at a local level do not cause extreme effects on service users' finances?

The PDS is concerned that the proposals outlined in the consultation may lead to people with Parkinson's and their families facing sudden increased in charges, particularly if the services they receive are provided for free or at reduced cost.

We would like to see the guidance clearly outline councils' responsibility to ensure that any changes to their charging policies do not cause hardship for their service users. This should emphasize that:

- increases in charges should be set at affordable levels
- people need to be informed in advance of forthcoming changes to charging policy
- the impact of charging policies must be monitored after any such change.

We would also like to see a stronger emphasis within the guidance that any resulting policy changes should be revenue neutral for local authorities.

4. Please identify any other matters / issues in the proposal that you feel remain unaddressed in relation to contributions towards a personal budget

Where payments for personal budgets are made net of contributions, it is essential that individuals are properly informed as to the amount of contributions that have been subtracted from the total and on what basis the calculation has been made.

The guidance should seek to ensure transparency where net contributions are used, requiring claimants to be informed how much they are contributing and the assessed figure for Disability Related Expenditure. This will enable

individuals to check that their charges are accurate and to challenge any unfair decisions.

About the Parkinson's Disease Society

The Parkinson's Disease Society (PDS) was established in 1969 and now has 30,000 members and over 330 local branches and support groups throughout the UK. The Society provides support, advice and information to people with Parkinson's, their carers, families and friends, and information and professional development opportunities to health and social services professionals involved in their management and care.

This year, the Society is expected to spend £4 million on research into Parkinson's Disease. The Society also develops models of good practice in service provision, such as community support, and campaigns for changes that will improve the lives of people affected by Parkinson's.

About Parkinson's disease

It is estimated that 120,000 people in the UK have Parkinson's and approximately 10,000 people are newly diagnosed with Parkinson's each year in the UK. Parkinson's is a progressive, fluctuating neurological disorder, which affects all aspects of daily living including talking, walking, swallowing and writing. The severity of symptoms can fluctuate, both from day to day and with rapid changes in functionality during the course of the day, including sudden 'freezing'.

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 20 will be diagnosed before the age of 40.

Parkinson's is a degenerative condition, although the speed of deterioration varies between individuals. One person may experience only slow and slight deterioration over years, while another person may report rapid decline in dexterity and mobility despite drug treatment. Symptom management is generally handled through prescribed medication and this can enable those in work to maintain their employment.

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