



## **Parkinson's Disease Society's response to the Department of Health consultation on the future of care and support in England**

### **Introduction**

The Parkinson's Disease Society welcomes this opportunity to comment on the proposals to reform care and support in England.

Our response is informed by feedback from discussions at nine branch and regional forum meetings from across England and discussion at a policy panel of people with Parkinson's and carers together with feedback from individual members.

Overall, there was widespread agreement that the social care system is in need of reform. However, it was emphasised that in addition to long-term reform the existing problems in social care need to be addressed as an immediate priority.

### **Topic 1 - a new care and support system**

**The government's vision is that people are supported to:**

- Live independently
- Stay healthy and recover quickly from illness
- Have as much control over their lives as possible
- Participate as active and equal citizens
- Live with or look after their family

#### **a) Do you agree with the vision for a new care and support system?**

Overall the vision was supported as an appropriate approach that reflected the needs of people with Parkinson's.

Clearly these are very broad principles and the detail will need to address a number of complex issues, for example how to balance the occasionally conflicting rights and needs of the carer and the person with the disability or condition.

One of the problems identified with the existing system is that services are provided "to suit the council," and not built around the needs of the individual. The vision is right to highlight the importance enabling people to live independently and giving them control over their own lives. However, there was concern that giving people control shouldn't mean local authorities "washing their hands of you," and local authorities must be given clear responsibilities to provide support and information to those managing their own care budgets.

There was a certain amount of scepticism about how the vision would be delivered and it was felt that there needed to be a clear set of rights that people could refer to and a body responsible for ensuring that these are delivered.

#### **b) Is there anything missing from this vision that you would like to add?**

### **i) Long term care needs should be a priority**

In addition to supporting people to stay healthy and recover quickly, the vision should address the need to support people to live with long-term, degenerative conditions. One of the problems with the current system is that eligibility criteria do not include sufficient requirement to take account of the long-term impact of a condition.

Risk assessment must take a long-term approach. Though a person might not be at 'immediate risk', assessment should consider whether failure to provide services will pose a significant risk in the longer-term. This is particularly relevant to people with degenerative long-term conditions such as Parkinson's, where preventative measures early on are often the most cost effective means of meeting the needs of people with Parkinson's and their carers.

Once identified, a person with a long-term condition should be brought under the umbrella of care services for the length of the condition. Assessments should include:

- Discussion of the long-term care needs likely to arise from a condition
- Ensuring that users and carers know where to go to for support
- Planning regular reassessments
- Planning for emergencies.

The vision should also include a commitment to supporting people in making informed decisions at key points in their life, including end of life care issues.

### **ii) Ending confusion about the distinction between health and social care**

"There needs to be a fairer and better system between health and social care."

Whatever shape the new system of care and support takes, there needs to be greater clarity about the responsibilities of NHS and local authority care services.

The new system needs to be transparent about which services will be funded by the NHS and which services are viewed as social care. During our consultation with members we heard from three people who were receiving free NHS continuing care, all of whom were initially assessed as needing social care services for which they were required to pay, and had had to appeal their decision.

Members taking part in a discussion at a London regional forum meeting raised concerns about 'charging creep' in their area, where previously free NHS services were now being labelled as social care and people were having to pay. This needs to be addressed: free NHS continuing care must continue and become easier to understand and access through a better integrated system of health and social care and a universal system of information.

At the same time there needs to be an integrated system of health and social care, focussed on the health and wellbeing of the population, with clear signposting and cooperation between services with GPs and information about both health and social care support available. PCTs should also have a

stronger role in supporting people to live in the community, with financial structures that reward investment in preventative measures.

### **iii) Inclusiveness**

Supporting all of those people with an illness, disability, or condition who are in need of support should be an underlying principle of any new system. Under the current system many of those who fund their own care are left to their own devices and often do not even get any advice, or information.<sup>1</sup>

Many people struggle to get the support they need, either because of lack of information about the support available or because of increasingly stringent eligibility criteria. Others delay seeking support from social services until they reach a crisis situation. The new system should seek to engage all people who are in need of support at an early stage.

### **iv) Seeking support needs to become routine and normal**

"You need to end the stigma of social care."

The current social care system is still tinged with a stigma that deters some people from seeking support. Ending this stigma will prove a considerable challenge, but is central to establishing a care system that meets the needs of an ageing society and should be included as a part of the vision of the strategy.

Seeking support and assistance needs to become routine and normal. A universal system of information and the availability of free preventative services for all early on in would both help the service become truly 'universal' and in doing so end the stigma.

### **c) To make this vision of independence, choice and control a reality what needs to change? What needs to be strengthened?**

#### **i) Information, advocacy and brokerage**

A universal information system that is widely advertised through both the health and care system is essential for any system of care to work. Currently people struggle to find out about the services they might be entitled to, for example: less than a third of carers responding to our 2008 members' survey were aware of their right to a carer's assessment<sup>2</sup>.

A national advice service linked to local authority areas would address the current confusion about where to turn to for information. Universal information would be an important step towards making the service universal. Nationally available information would need to be supported by a system of local advocacy and brokerage to enable people to claim the services they are entitled to.

In our discussions with members, there was strong support for one body clearly responsible for ensuring that people can get information about services. This should include information about, and signposting to, services and support, information about what people will be charged for and how much they will be

charged, and a clear point of contact for every client. It was felt that this change should be introduced as soon as possible.

### **ii) A greater focus on preventative services**

Encouraging preventative measures should be central to any system of care and support. Low level interventions at an early stage can be of enormous benefit to people with Parkinson's and their carers and are frequently cost-effective in the long-term.

During discussions with members there was very strong support for certain preventative services being provided for free; including funding for aids and adaptations and respite services for carers. Such interventions would more than pay for themselves in the long term in saving to the health and care system.

### **iii) Simple and transparent**

There was a clear message from the people with Parkinson's we spoke to that the current system is too confusing, both in terms of identifying support available and in working out what you have to pay. The system needs to be easy to understand with clarity about where to turn to for support, types of support available and the cost of services.

The system must also be easy to access – with an identifiable body responsible for ensuring that all potential users and carers have access to information about services, eligibility criteria, charging and signposting to services.

## **Topic 2 - how can we meet care and support needs**

**How should the responsibility for meeting care and support needs in the future be shared out between the following groups:**

- People who need care and support
- The families of people who need care and support
- Everyone in society
- Government

### **Who should contribute more for care and support in the future?**

#### **i) People who need care and support**

It was felt that there should be some limit to the amount of care that people pay. The current means tested system was widely criticised as “unjust” or “unfair”, because those that had savings above the means-tested level faced a lifetime of charges, and often felt abandoned by social services if they paid for private care.

Though most people with savings were happy to make a contribution to the cost of their own care, they objected to having to pay for the full cost of their care and for having to pay this for the rest of their lifetime. It was widely agreed that there should be some limit to the contribution made by individuals.

Many also objected to the lack of information and advice available to those paying for their own care and felt that whatever system was introduced needed to embrace all of those people using care services.

“If you’ve planned or saved you get nothing.”

## **ii) Role of family and carers**

Increasing the ability of carers to provide support for family members is essential. Research by carers UK<sup>3</sup> suggests that in order to retain the same balance of informal care in light of an ageing population the number of family carers would need to increase from 6 million to 9 million. There are factors that make this increase difficult to achieve, including smaller families, more people living alone and increasing geographic mobility amongst families.

However, families cannot be forced to care for their relatives and people should not face additional costs if they live alone or if their family are unable to care because of work or similar commitments. Rather, improved support and incentives are essential to ensure that carers are able to balance their caring role with work and other commitments.

A review of carers benefits is needed urgently. At £50.55 per week, Carer’s Allowance is the lowest income-replacement benefit and overlapping benefit rules mean that most people in receipt of a pension do not qualify for any additional support.

Currently carers tell us that they feel taken for granted and there needs to be appropriate financial recognition for their caring role. A review of the benefits provided to carers is needed urgently to address these problems. Depending on how the new system of care is funded there could be some form of credit paid to family members providing care; for example if paid for by an increase in National Insurance carers could be given National Insurance Credits.

“When you’ve spend years looking after someone as a carer, forfeited your savings, why should you have to pay?”

There was also a strong feeling from members we spoke to that families should not be expected to pay for the cost of their relative’s care.

## **iii) Government**

Overall there was recognition that the government would have to increase its contribution. It was felt that if an additional £6 billion or more per year is needed then a significant proportion of this additional funding should come from government.

There was relatively strong support for the whole of the additional costs to come from government, raised by national insurance.

“Government needs to take the bull by the horns and spend the money.”

## **iv) Everyone in society**

Overall there was broad support for the introduction, in the long-term, of a system that required everyone who could afford it to make some contribution to the cost of care, though there was no agreement over which type of models was preferable.

One of the problems with the current system is that many people assume that their National Insurance contributions cover social care, and are left unprepared for meeting social care costs. The reform of the care system needs to leave people with a clear understanding of the contribution they will have to make to their own care costs. It was also felt that people should be able to choose between various options for funding their care costs.

However, the model of compulsory private insurance was not popular amongst our membership. In several instances people cited examples of not being able to get insurance because of their condition and doubted that people with a disability would get the support they needed through such a system. One individual reported that he had private medical insurance but that the insurer had managed to “find a loop-hole,” and had refused to pay for any of his costs when he was diagnosed with Parkinson’s. In this instance, of course, the individual was able to obtain health care services from the NHS, but he was greatly concerned that similar loopholes would emerge in any system of social care insurance.

### **Topic 3 - Setting fair rules for government's contribution**

#### **Topic 3 a - who should decide how to spend the money In the future, should central government or local government decide who is entitled to help and what they are entitled to?**

"There needs to be someone responsible regardless of who pays."
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Throughout our discussions with branches and members there was widespread agreement that the current system was too much of a ‘postcode lottery’.

There was strong support for some universal minimal standard and level of care that would apply across England, including a clear statement of what level of need will result in entitlement to services and a guarantee of services to meet that need.

Above all people wanted clarity about who is responsible for ensuring that they get support, regardless of whether this was supplied through a national or local body, with one basic system that could be understood wherever you live. It was also felt that systems for individual/personal budgets should follow a standard system across the country.

A few individuals expressed concern that if some of the existing responsibilities were removed from local authorities this would take away democratic accountability, but overall it was felt that there needed to be some form of national body who could hold local authorities to account in order to ensure that people in need were not being denied care.

One of the discussions focussed on the problem of moving house and the lack of portability of social care entitlement. It was recognised that there was a limit to the practicality of a 100% right to portability, as a rural area couldn't provide

the same services as a large town, but it was felt that people could have an assumed right to the same package they currently receive unless the authority are able to show exceptional reason why this isn't appropriate.

### **Topic 3 b - should we give more support to those with low incomes and assets?**

**In the future, should the same help be given to everyone who needs it or should the government give more help to people who have low incomes and assets?**

“The solution needs to be fair to those with nothing and those with a lot – this isn't easy.”

There was no clear agreement about how the system should distribute government funding between those that have saved and those that can't pay; it was recognised that there is no straightforward answer to this and most people we spoke felt that the system needed to both reward those that have saved and provide a safety net to those unable to save or plan for their care costs.

On one hand, there was a very strong message that the current system is overly focussed on providing care to those with low incomes and that more needs to be done to support those that do pay for their own care. It was also felt that the current means tested system focussed on assets and savings without taking into account that many people with assets may be on low incomes, for example people with Parkinson's who retired early because of the condition and have no means to supplement their income.

“If I go into a home my wife loses the house.”

There was, however, recognition that not all people were able to pay for care services. In particular it was noted that many people with long-term disability will not have had the opportunity to set aside money for their care needs, and that any system needed to include provision for those unable to make plans for their long-term care needs.

### **Topic 3 c - should the care and support system be different for people with different needs**

**In the future, should the same care be given to everyone who needs it or should government give more help to people who are unable to plan and prepare for their own care and support?**

There was a strong feeling amongst the people with Parkinson's we spoke that those with long-term conditions need to be treated differently from other clients.

People living with a long-term condition face a lifetime of costs relating to the condition and in many cases no opportunity to earn the income to pay for these services. The average age of diagnosis for Parkinson's Disease is between 50 and 60 years of age, and one in twenty are diagnosed before the age of 40. Nearly a fifth (19%) of respondents to our members' survey had retired early because of the condition, with 7% retiring before the age of 45.

In discussion with members and branches, many people complained that though they have savings and assets above the current means-tested limit they have a low income and no opportunity to go back to work. Their savings have to pay for a lifetime of care, and we often hear of people refusing services because they can't afford it.

Whatever system is introduced, it is important that it takes into account a person's ability to pay over the lifetime of the condition.

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

### **About the Parkinson's Disease Society**

The Parkinson's Disease Society (PDS) was established in 1969 and now has 29,000 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.

### **References**

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<sup>1</sup> *Self-funded social care for older people: an analysis of eligibility, variations and future projections*, Commission for Social Care Inspectorate, 2008

<sup>2</sup> *Life with Parkinson's today – room for improvement*, Parkinson's Disease Society, 2008

<sup>3</sup> *It Could be You... ? The Chances of Becoming a carer*, Carers UK 2001