



Parkinson's Disease Society response to Paying for Care in Wales

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

Our response is informed by feedback from across Wales from individuals with Parkinson's, carers and branch discussions of the issue.

Sharing the responsibility for paying for care

Who should contribute more for care in the future?

In order to be sustainable any system of social care requires a combination of funding from government, individuals and everyone in society; which doesn't place an unfair burden on those individuals that use services or their families; whilst ensuring a minimum standard of support for those that have not been able to make any provision for their long-term care needs.

PDS members in Wales have identified a number of problems with the current means tested system. Though most people with savings were happy to make a contribution to the cost of their own care, the current system was described as an "all or nothing" system, where those just over the charging threshold face having to pay for the full cost of their care for the rest of their lifetime whilst others pay nothing. In addition, those paying for private care often feel abandoned by social services, finding it difficult to get information or advice if they are paying for their own support.

Given that additional funding will be needed to provide care for an ageing population, the government must contribute a significant proportion of this additional funding. PDS members have stressed that care users should not be expected to pick up the full amount of this additional cost.

In the long-term, a system that required everyone who could afford it to make some contribution to the cost of care would seem to be a sensible way forward. However, PDS members have expressed concern with proposals for a model of compulsory private insurance, citing difficulties making claims or getting insurance cover and stressed that people should be able to choose between various options for funding their care costs.

Whatever system for funding care is introduced, it is essential that it is absolutely transparent; people must have a clear understanding of the contribution they will have to make towards care costs. Those paying for their

own care should still be able to access advice and support from social care staff.

Families should not be forced to care for their relatives nor should families be expected to pay for the cost of their relative's care. Improved support for carers is essential to enable families and carers to continue to play their role in supporting people with illness and disability.

Setting fair rules for financial support in the future

National or local?

There is a need for a universal minimum standard of care that would apply across the country, with clarity as to the level of need that would result in entitlement to services and a guarantee of services to meet that need. The way services are delivered should be decided locally, with these decisions incorporating the views of services users and carers.

There needs to be clarity about who is responsible for ensuring that people get support, regardless of whether this is supplied through a national or local body, with one universal system that could be understood wherever they live.

Different systems for different needs?

The PDS believes that any system for funding social care must take account of the long-term costs of living with a long-term condition and a person's ability to pay over the lifetime of the condition.

One of the problems that our members have identified with the current means-tested system is that although people might have assets above the means-tested limit, they are likely to have a low income and no opportunity to return to work. Consequently, their savings have to pay for a life-time of care.

One carer in Cardiff described how he had to fight his local authority in order **NOT** to get the additional care services they said he needed (and which they tried to impose on him) because he knew that he would be charged for these services and couldn't afford the charges.

More support for people with low income and few assets?

Any system for funding / delivering care must include provision for those unable to make plans for their long-term care needs. Many people with a long-term disability or condition will not have the opportunity to set aside money for their care needs. Whatever reforms are introduced, the Government should continue to provide a safety net for those with insufficient income or savings to meet their care costs.

General comments

Ending confusion about the distinction between health and social care

Though this consultation is focused on funding of social care services, consideration needs to be given as to how to address the current confusion

about the respective responsibilities of NHS and local authority services, and how to ensure effective joined up working between the two sectors.

The new system needs to be transparent as to which services will be funded by the NHS and which are social care services. 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 and information about health and social care routinely provided.

One solution might be to require authorities and health trusts to identify a joint 'pot' of money for health and social care and for the services to be delivered jointly through combined health and social care bodies.

Information, advocacy and brokerage

"The main issue that all of them (carers) reported was that they didn't know what support was available, so they weren't getting anything."
Feedback from a discussion of the consultation by carers of people with Parkinson's in Bridgend

A universal information system is essential to ensure that the care system is effective and there for people when they need it. Currently people struggle to find out about the services they might be entitled to. In Wales, two thirds of carer respondents to our members survey last year did not know about their right to a carer's assessment.¹

Information should be automatically available to those that need it. The Welsh Assembly Government should aspire to developing a health and social care workforce that is proactive in informing people of the support available.

A national advice service linked to local authority areas would go some way to addressing the current confusion about where to turn for information. National 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.

Seeking support needs to become routine and free from stigma

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.

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 would both help the service become truly 'universal' and in doing so end the stigma.

Role of family and carers

Increasing the ability of carers to provide support for family members is essential. Research by carers UK² 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.

"I have asked for an assessment, I'm still waiting 9 months later."

There is generally very low awareness amongst carers of their right to an assessment. Carers from across Wales at a PDS carers focus group last year reported that they had never been told about their right to a carer's assessment. One carer had never had an assessment in 12 years of caring. Improving information for carers is an essential part of the solution to the provision of care and the PDS welcomes the Legislative Competence Order recently laid by Gwenda Thomas AM.

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, including 23 in Wales. 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 6,000 people in Wales have Parkinson's. 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

¹ *Life with Parkinson's Today – room for improvement*, Parkinson's Disease Society, 2008

² *It Could be You... ? The Chances of Becoming a carer*, Carers UK 2001