

**Health and Social Care Committee  
Inquiry into residential care for older people**

**RC26 – Parkinson's UK Cymru**

**Parkinson's UK's response to National Assembly for Wales' health and social care committee inquiry into residential care for older people**

Parkinson's UK welcomes the opportunity to provide input to the inquiry into residential care for older people. Our submission comprises information provided by people with Parkinson's, and staff members. It includes a separate submission from a relative – *please see appendix at the end*. Our responses relate primarily to the first three points of the inquiry, with one relating to the fourth point on regulation and inspection.

- 1. Process by which older people enter residential care and availability and accessibility of alternative community-based services**
  - 2. Capacity of residential care sector to meet the demand for services from older people in terms of staffing resources**
  - 3. Quality of residential care services and the experiences of service users and their families; the effectiveness of services at meeting the diversity of needs amongst older people.**
  - 4. effectiveness of regulation and inspection arrangements**
- There is a lack of quality and practical information and support on tap for people and their families on the cusp of making the transition from their familial home to a residential/nursing one. Self funders are often given even less information and support than others. If they're lucky, they or a family member may be given a written list of local care homes, but we are aware of someone who was told by social services that such a list exists and that was it – no further help was provided. Many people don't have information or help in claiming any benefits they are entitled to.
  - Little or no thought is given to the input a partner/carer could have in assisting the care package e.g. psychological and emotional support. e.g. how far to travel for visiting etc
  - Counselling and support for carers to deal with feelings of guilt and change of lifestyle is needed.
  - There is poor monitoring of a person's well being/progression of condition to aid provision of quality care and cases for continuing health care.
  - There are poor levels of cleanliness in many homes
  - There is a lack of consistency of staff – probably due to low pay, poor working terms and conditions, long shifts and little chance of promotion.
  - There is a lack of awareness and understanding of Parkinson's amongst staff, particularly how the condition varies from day to day.

- In one residential home, feedback from partners/carers indicated a general caring attitude by staff, but a lack of attention to detail and a great variation in care according to which carers were on duty. They often seemed to be short staffed and there were issues with one client who did not appear to be properly cared for in terms of personal hygiene
- Those homes that are well run and put the resident first are usually managed by individuals with a strong sense of duty to their service users and their families and have an open door policy. A very positive step used by some is to include family members on interview panels.
- We recommend that spot check inspections should be the norm in order to gain a true picture of how homes are being run and to ensure consistency of good practice.

**The following is an extract from our policy statement on [Funding and delivering long term care](#), developed with people with Parkinson's. It provides further information and evidence on some of the issues being looked at by the inquiry:**

### **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 local health bodies must work together to deliver joined-up support for people with Parkinson's.
- The contribution of carers should be properly recognised, with appropriate support, including respite, provided to those who need it.
- Services should be flexible and built around the needs of the individual, who 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.
- A long term approach must be taken to assessing need and providing support, recognising that Parkinson's is long term fluctuating condition.
- 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 avoid unnecessary admission to residential care and include self-management where appropriate.
- National standards for commissioners and providers must be in place to ensure high quality care services, and performance against these standards should be monitored, regulated and enforced against where people's experiences of care are poor.
- People should 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 about Parkinson's and services must be appropriate for people with long term, fluctuating conditions.

- There should be a national approach to adult social care workforce, to ensure they have an equal status to the healthcare workforce and meet national standards of care.

## **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. Ultimately care needs are such that a person is likely to 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 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.<sup>1</sup> 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.

### **Information and choice**

Information about services and support is often not easily available, and 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 be of a level to ensure they can buy a service of their choice.

### **Rationing**

There is a perception that the current system is driven by local authority budgets and services available rather than meeting the needs of users. This is most commonly expressed in the social care eligibility criteria in operation, with a number of authorities providing services only for those with "critical" or "substantial" care needs. This has led to people with Parkinson's being unable to get the support they need or who have been told that support was being withdrawn for no reason.

### **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. The lack of integration means health and social care budgets can become a battleground, with the person at the centre confused as to where the boundary between health and social care lies. This is most apparent with NHS

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<sup>1</sup> Note that free personal and nursing care in Scotland for those over 65 may mean less of a financial impact on those who are eligible for social care, as the state is contributing towards people's care costs in nursing homes, care homes and in their own homes.

continuing care.<sup>2</sup> 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.

## 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. There are concerns that the way services are commissioned can be rigid and inflexible, leaving people feeling rushed and neglected. Issues around protection of vulnerable adults remain a concern. 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?

### Findings from survey and inquiry

There is clear evidence of unmet need amongst people with Parkinson's. A survey of Parkinson's UK members<sup>3</sup> found, for example, that of the 26% of people with Parkinson's who needed personal care services, such as help with dressing or bathing, one in five (19%) were not receiving this support. One in ten respondents said that their home was unsuitable to live in, because it needed adaptations or because of steps or stairs. Of those who purchased the equipment they needed to live at home, many did so without professional advice, for example 49% of those purchasing bathroom aids and 43% of those installing ramps or rails outside their house.

There is a need for better information. People with Parkinson's and their carers do not know about the support available and their right to assessment. For example, our recent membership survey identified that only 11% of carers were actually receiving support from social services, a fall from 16% in the 1997 survey. Seven out of ten carers were not aware of their right to a carer's assessment.

These findings were reiterated in a parliamentary inquiry<sup>4</sup> on services for people with Parkinson's.

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<sup>2</sup> Please see our policy position statement NHS continuing care (2010)

<sup>3</sup> Parkinson's UK. *Life with Parkinson's today – room for improvement*. (2008)

<sup>4</sup> All Party Parliamentary Group for Parkinson's Disease. *Please mind the gap – Parkinson's disease services today* (2009).

## About Parkinson's UK

Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone.

We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's.

As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services.

Our work is totally dependent on donations. Help us to find a cure and improve life for everyone affected by Parkinson's.

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## Appendix

The following was submitted by a relative:

In response to your request for feedback you are welcome to make any use you wish of info below and I am happy to give oral evidence if required.

### Re paragraph 1: 'accessibility of alternative community-based services'

Though extremely and unfairly expensive I found this support very easy to access, generally of good quality and very effective. (I set up my own care plan to keep my Mum in her home as was her wish, building up from an hour's support a day to 24/7 using a number of private domiciliary care agencies over

a period of 5 years.) Mum's assessed entitlement to care by Social Services was far from adequate for a number of reasons. Although the personnel did their best, the system they are locked into does not, from my observations, work in the best interests of those they serve. This is basically because the system is understaffed and under resourced (resulting unreliable punctuality, inappropriate visiting times which are far too short anyway, many carers overstressed, many not properly trained, low morale, lack of continuity because of frequent staff changes, lack of communication, not enough flexibility to meet individual needs.....).

With regards to access to community based OTs and Physio advice - I always had a prompt and excellent response to requests for assessment/advice to carers as Mum's health/mobility declined. I also had an excellent response from the District Nurse team but there were times when they were understaffed meaning that insufficient visits could be made to monitor and treat Mum's pressure sore. Services providing items such as handrails, slip sheets, pressure cushions, bath lifts, hoists etc - all excellent with the exception of the acquisition of a hospital bed and a ripple mattress (apparently these are 'post code lottery' items). Gwent Care and Repair Service - fantastic.

### Re paragraph 3: 'the experience of service users and their families'

Mum presently receiving excellent care in a residential/nursing home though from what I understand (talking to many carers/friends with parents in homes) most homes, though 'task efficient' regarding physical care, lack in the provision of supporting individual 'emotional well being' - life is too institutionalised. While making residential care more like 'home' is an undoubted challenge I doubt there is much transfer of expertise from 'beacon' homes or enough finance to access advice from Specialist Nurses (e/g Parkinson's Nurses). Catering for a diversity of needs requires additional staff, physical care is just not enough. ***There's something huge missing between living at home and being in a home*** ... there's got to be a way we can improve this (greater interaction with local community especially local schools, better accommodation to allow quality whole family visits in a private comfy room, additional staff to allow time to encourage greater independence and purposeful activities.... improved indoor environment and greater access to garden areas). My greatest heart ache is the tremendous change in Mum's emotional/well being between what a home provides and what was provided for her at home.

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