

Inquiry into regulation of care for older people

Parkinson's UK

Parkinson's UK strongly welcomes the outcomes of the Health and Sport Committee's Inquiry to date. We are pleased that many of the points that we raised in our initial submission were addressed in the committee's report and the Scottish Government's response to it.

Care regulation is of particular importance for people with Parkinson's and their families. People with Parkinson's are potentially at extremely high risk of substandard care, neglect and abuse. This is because of the range of symptoms and medication side effects that people commonly experience in later-stage Parkinson's. These often include significant communication issues, cognitive difficulties including dementia, mental health symptoms and movement problems. In addition, people with Parkinson's rely on complex medication regimes to manage their symptoms. If they do not take their medication at the right time and at the right dose, symptoms can become uncontrolled.

We particularly welcome the following outcomes:

- Frequency of unannounced inspections of all care services to be increased to one year
- Commitment to Continuing Professional Development of social care professionals as part of the process of workforce registration
- Involvement of health and social care professionals in the inspection process through the Care Inspectorate's questionnaire
- Research into the staffing mix required in different care settings
- Measures to promote the duty of all health and social care staff to take action when residents and service users are at risk

However, we would like to raise a number of issues:

Risk based approach to Inspections

Parkinson's UK is supportive of the principles of risk-based assessment within the context of annual assessments for all services. However, we remain to be convinced that self-assessment should form the basis of the RSA. We agree with other contributors that this may measure a service provider's ability to manage paperwork, rather than the care it is providing. As the highly publicised failings of the self assessment model in predicting risk relating to Hospital Acquired Infection (HAI) in England and at Vale of Leven show, service providers cannot always be relied upon to be accurate about their services.

Some of the actions taken partially address our concerns about RSA. We welcome the external validation research undertaken by Glasgow Caledonian University. In addition, the introduction of annual unannounced inspections goes some way towards removing the potential conflict of interest whereby

positive self assessment results would reduce the likelihood of an inspection, which gave service providers an incentive to present themselves in a positive light.

Parkinson's UK also welcomes the involvement of health and care professionals in the RSA process, and believe that Parkinson's nurse specialists would be particularly well-placed to assess whether people's care is impacting positively or negatively on their condition.

However, we are concerned that safeguards should be in place so that employees feel able to respond honestly where improvements are needed. We feel that health professionals who wish to work with clients living in care homes, or those who receive income from care providers for providing a service may also require assurances that any information they provide will not compromise their position.

Involvement of service users and carers in regulation and complaints

Although there are several statements supporting increased involvement from people using services and carers in all aspects of the process, there is a real lack of detail about how these opportunities would be extended in practice. We believe that people's experiences are central to assessing quality of care, yet the Scottish Government's response suggests that this remains as an aspiration for future work.

We hope that more detail will be forthcoming with concrete proposals and timescales for implementation.

Parkinson's UK urges the Care Inspectorate to ensure that plans to involve service users in all aspects of regulation include strategies to include those who are at highest risk, including those with communication support needs and/ or dementia who may find it difficult to participate in conventional focus group or survey work.

We are concerned that, despite the support from all parties for the principles of independent advocacy support to enable people to be involved in the regulation and complaints process, access to independent advocacy is not considered as part of the regulation process. In addition, there are ongoing funding issues for organisations that provide this type of support to care home residents and other older people. Unless these are addressed, it is increasingly unlikely that people will be able to access an independent advocate. Parkinson's UK believes that, while health and social care staff have an important role in advocating on behalf of their patients / clients, this is not the same as the support that an independent advocate can provide, particularly during a complaints process where conflicts of interest may arise.

Involvement for service users with communication support needs was not addressed in the Inquiry. This is a significant issue for people with Parkinson's, and is also common in a number of other long term conditions. It

is a major barrier to participation that should be addressed explicitly in respect of service user and care involvement.

Access to healthcare for care home residents, including specialist healthcare and pharmacy

In common with the Committee, and other bodies, Parkinson's UK has concerns that the proportion of qualified nurses working in care homes has fallen, at the same time as levels of frailty and complex needs amongst residents have increased. People with Parkinson's frequently have complex needs that require nursing support. The Care Inspectorate's research into skill mix across all care settings is a welcome first step in establishing the extent to which skill mix impacts on care.

The research is, however, limited. There is nothing in the Scottish Government's response to suggest that care providers will have to provide staffing cover in line with the research recommendations when it is published. This research will have very limited impact without levers to apply the findings in practice.

Parkinson's UK remains concerned about access to specialist healthcare amongst care home residents. This concern has not been addressed by the Inquiry to date. The NHS Healthcare Improvement Scotland Clinical Standards for Neurological Health Services¹ state that people with Parkinson's require specialist care, provided by specialist multi-disciplinary teams, including specialist nurses. As the condition progresses, people's medical needs increase. Yet in many parts of Scotland, people lose contact with their Parkinson's multi disciplinary team when they are admitted to care homes. This can lead to a significant deterioration in people's symptoms. Parkinson's UK believes that care home residents with complex needs should retain access to specialist multi disciplinary teams, and that this should be assessed as part of the inspection process.

We note with interest the Scottish Government's comments on the applicability of the Chronic Medication Service to care home residents. It states that residents *"often ... have complex needs requiring a level of pharmaceutical care similar to that provided by clinical pharmacists in the hospital sector who work in partnership with medical and nursing staff"*. This will certainly be the case for many people with Parkinson's who typically require a complicated medication regime to manage their Parkinson's symptoms and to control side effects.

The NHS Clinical Standards for neurological health services² make clear that people with Parkinson's must receive the correct medication at the correct time and the correct dose to keep their symptoms controlled. However, the experience of people with Parkinson's and their carers suggests that this is often not understood by care home staff, and that the level of pharmaceutical care provided to care home residents is often very poor. Medication management for people with Parkinson's is a central aspect of the free Education and Training sessions that Parkinson's UK offers to care home staff

throughout Scotland and the UK. We have achieved good coverage of this training across Scotland, but can only offer this to care homes that opt to receive this service. We would strongly support action to embed better support for effective pharmaceutical management processes throughout the social care system.

Future of the National Care Standards

We agree that the National Care Standards should be reviewed, or replaced by other national standards. We believe that any new Standards should include a specific right of access to independent advocacy, communication support and participation. We would also prioritise the right for care home residents to have access to the same healthcare resources as people who do not live in care homes.

Data collection and monitoring

Parkinson's UK agrees with the committee's recommendation that data should be collected on unscheduled admissions from care homes, and agrees with the Scottish Government's points on the need to ensure that the data is subject to further analysis to understand the reasons for admission, both so that prevention activities can be implemented where appropriate (eg to prevent falls) and so that poor or dangerous care homes can be identified. This data collection is also important to ensure that there is no perverse incentive for care homes to avoid appropriate hospital admissions. If this data is not interrogated and a hospital admission automatically triggers negative attention from the Care Inspectorate, this could create a climate where providers avoid any hospital admission, which would endanger people with Parkinson's and other residents with complex needs.

While it is essential to reduce unnecessary hospital admissions, and to implement good care planning to avoid these, people with Parkinson's remain at high risk of complications that require hospital admission. About one in every four people with Parkinson's in Scotland are admitted to a hospital at least once in a year, and over half of these admissions are unplanned.³ One in every ten people with Parkinson's in Scotland is classified by SPARRA as at high risk of hospital admission in the next year.⁴

Commissioning and procurement

We highlighted our concerns about the Care Inspectorate's limited role in scrutinising commissioning and procurement practice, and in particular its inability to impose sanctions where commissioning practice is poor. We welcome commitments from the Scottish Government and Care Inspectorate to look at this area again, although we are concerned that "resource implications" may impede progress.

Parkinson's UK believes that it is essential that competition should be based on quality, not on price, and we therefore welcome the model adopted by Edinburgh City Council to consider findings from the Care Inspectorate within

its procurement processes, and believe that measures are needed to encourage other local authorities to adopt this approach.

Financial oversight

The Inquiry has raised significant issues around the financial oversight of care providers. This is a very complex area because of the varied nature of social care providers, but Parkinson's UK believes that it is essential that finances and business models are subject to scrutiny, as the consequences of company failure are so serious for service users, their families, local authorities and staff. Parkinson's UK supports Age UK's view that contracts with care providers should stipulate a minimum of six months notice of closure or deregistration, and that this should be a requirement for registration.⁵

We welcome the new guidance of financial viability for the Care Inspectorate, and the Scottish Government's ongoing work with COSLA and others to develop recommendations within Scotland and with the UK Government on financial issues relating to cross border and transnational businesses.

About Parkinson's

About 10,000 people in Scotland have Parkinson's.

Parkinson's is a progressive, fluctuating neurological disorder, which affects all aspects of daily living including talking, walking, swallowing and writing. People with Parkinson's often find it hard to move freely. Their muscles can become stiff and sometimes they freeze suddenly when moving. There are also other issues such as tiredness, pain, depression, dementia, compulsive behaviours and continence problems which can have a huge impact on peoples' day-to-day lives. 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'. There is no cure.

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, and the incidence increases with age. Most people living with Parkinson's are over 65. However, one in seven people with Parkinson's will be diagnosed before the age of 50 and one in twenty are diagnosed before the age of 40.

About Parkinson's UK

For more information, please contact our Parliamentary and Campaigns Officer, Tanith Muller, email: tmuller@parkinsons.org.uk, telephone 0844 225 3726.

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.

We have a dedicated staff team in Scotland, and local groups across the country supporting people affected by Parkinson's.

Tanith Muller
Parliamentary and Campaigns Officer, Scotland
Parkinson's UK

¹ NHS QIS (2010) Clinical Standards for Neurological Health Services. Edinburgh: NHS Quality Improvement Scotland.

² NHS QIS (2010) Clinical Standards for Neurological Health Services. Edinburgh: NHS Quality Improvement Scotland.

³ Parkinson's UK analysis of ISD Data, 2009. Unpublished.

⁴ Based on a crude population prevalence of 10,000 people with Parkinson's in Scotland, and ISD SPARRA figures predicting a greater than 50% risk of hospital admission in the next year. ISD (2011) SPARRA database: Number of patients in Scotland at risk of emergency admission / readmission, in the period 1st July 2011 - 30th June 2012, by risk probability group, and those with an admission history of Parkinson's Disease. Unpublished data.

Reference: /conf/sparralive/Ad Hoc/Parkinsons UK

⁵ Age UK 2011 Written Evidence to the Health Select Committee's 14th report on Social Care <http://www.publications.parliament.uk/pa/cm201012/cmselect/cmhealth/1583/1583we06.htm>