Inquiry into regulation of care for older people

Parkinson’s UK

Parkinson’s UK welcomes the opportunity to contribute to this Inquiry. However, we note that the new regulatory framework has only been in place since SCWII was established earlier this year, so our comments largely reflect historic experience.

About Parkinson’s

About 10,000 people in Scotland people 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.

Parkinson’s and social care

People with Parkinson’s and their unpaid carers typically require high levels of social care as the condition progresses, both at home and in care homes.

Parkinson’s symptoms often include a combination of physical disability, cognitive deficits and communication problems. People with Parkinson’s rely on complex medication regimens to manage their symptoms, and if they do not take their medication at the right time and at the right dose, this can lead to uncontrolled symptoms. The complex nature of Parkinson’s can mean that people are particularly vulnerable to substandard care, neglect and abuse, and may be less able to make their concerns known.

Does the regulatory system ensure care services for older people are providing good quality and appropriate care?

Because people with Parkinson’s are often particularly at risk, Parkinson’s UK believes that it is essential that care regulation is rigorous and responsive. We are concerned that current regulatory systems are insufficient to ensure that care services for older people are providing good quality and appropriate care.
In the face of greater reliance on self assessment and a 25% budget reduction for SCSWIS, we believe that there is an increased risk that poor and dangerous services could be missed.

**Can we be confident that the regulatory system is picking up on care services where the quality of care is poor?**

Parkinson’s UK has major concerns about the quality of social care across all settings.

It is often extremely difficult for people with Parkinson’s and their families to navigate the care system, and they tell us that they are not confident that information on services can be trusted. Services can be rigid and inflexible, with 15 minute home visits, people being put to bed or woken at inappropriate times, or busy care home staff leaving people feeling rushed and neglected. People are often unable to access the overnight support that they need. 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 social care have insufficient understanding of their condition.

It can be argued that the bar for “satisfactory” services is set so low that it is rare for people to receive the high quality care to which everyone should be entitled. In this context, the examples listed above do not qualify as “poor care”. Low standards are demoralising for all involved. They can also make it harder for service users, their families and friends or professional whistleblowers to speak out, or be taken seriously when they raise concerns.

Parkinson’s UK believes that the regulatory system sometimes fails to pick up on very poor quality care. As the recent example of the Elsie Inglis care home in Edinburgh has shown, even where the regulator had conducted a recent inspection which highlighted concerns, the home was able to continue operating until one resident died.

**Are there any particular weaknesses in the current system?**

Parkinson’s UK has identified a number of weaknesses in the current system. These are:

- **self assessment**

  Parkinson’s UK believes that the use of self assessment to establish risk is problematic as it depends on the service provider accurately representing its service. It may measure a service provider’s ability to manage paperwork, rather than the care it is providing. Because self assessment results are related to inspection, service providers have an incentive to present themselves in a positive light. It is not clear that the possibility of an unannounced inspection is sufficient to correct this. 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 be relied upon to be accurate about their services.
- **Timing of visits**
  Under the current model, it can be up to two years between inspections. We believe that this is too long.

- **Access to specialist health services**
  The National Care Standards for care homes include several provisions relating to health, and state that people should have reviews of their healthcare needs and access to relevant professionals. The experience of most people with Parkinson’s suggests that this standard is not being met. In most parts of Scotland, people lose contact with their Parkinson’s multidisciplinary team when they are admitted to care homes. This can lead to a significant deterioration in people’s symptoms as their condition enters its most clinically challenging stages. Parkinson’s UK believes that care home residents with complex conditions like Parkinson’s should retain access to specialist multidisciplinary teams, and that this access should be assessed as part of the inspection process.

- **Staff training**
  People with Parkinson’s consistently report that they feel that professionals do not have the required knowledge about their condition. This lack of training has a direct impact on care. Understanding issues including the fluctuating nature of Parkinson’s and the need for medication to be delivered on time, every time, are essential to delivering good quality person-centred care for people with this condition. There is no current regulatory requirement for service providers to ensure that staff have a good understanding of the needs of the people that they work with.

Parkinson’s UK offers a free education and training service for social care providers. We have achieved good coverage across Scottish care services, and the service has evaluated positively, but it is difficult to persuade some providers to take up the offer of training if there is no regulatory requirement for training of this kind.

- **Financial oversight**
  Recent issues with Southern Cross raise significant concerns that there is no regulatory oversight of care providers’ financial affairs. There is considerable uncertainty for service users, as well as pressure for local authorities to provide emergency cover if care companies cease operating. Parkinson’s UK believes that there should be regulatory oversight of the finances of care companies to reduce the risk of sudden closure.

- **Commissioning and procurement**
  SCSWIS has a limited role in scrutinising commissioning and procurement. While Parkinson’s UK believes that Scotland’s approach contrasts positively with England, where no similar function is undertaken by the regulator, we feel that this role should be strengthened. We believe that there are inextricable links between the way care is commissioned (for example commissioners contracting and paying for 15 minute packages of homecare) and the quality of services experienced. However, although
SCSWI has the potential to work in this area, it has no power to intervene or impose sanctions if commissioning practice is poor. This should be remedied.

**Does the system adequately take into account the views of service users?**

Parkinson’s UK notes that the “involving people” section of the SCSWI website is currently blank, which may suggest that this area of work has less importance than others. In general, the Care Commission materials that are still available acknowledge many of the difficulties that people face in giving their views. However, Parkinson’s UK is concerned that this good practice remains widely unfollowed.

The dynamics of care may make it particularly difficult for any service user to provide honest feedback. People frequently lose confidence when they make the transition to receiving higher levels of care or moving into a care home, which makes it more difficult to provide negative feedback or raise concerns. People also find it harder to raise concerns if they fear reprisals from people who provide their care. This is particularly the case if abuse is taking place, but can also be a problematic in any care environment, because service providers can exercise less threatening forms of control over service users, sometimes unwittingly.

For people with communication difficulties, the provision of communication support will be essential if they are to participate. It is not clear whether SCSWI inspectors offer this support when trying to speak directly to service users.

We are concerned that the Care Standards do not recognise the importance of access to independent advocacy. People with highly complex needs are particularly likely to require additional support to communicate their views about their care, yet unlike within the NHS under the Patient Rights Act, there is no requirement to inform social care service users about their right to advocacy. While SCSWIS Includes information about advocacy in its “how to complain” leaflet, it is disappointing that it only establishes access to advocacy as a criteria to qualify for “excellent” people involvement. It is not clear whether inspectors would encourage it involvement from advocates when inspecting services.

**Does the registration and regulatory system provide an appropriate basis for the regulation, inspection and enforcement of integrated social and NHS care in the community?**

The current registration and regulatory regime reinforces the barriers between health and social care, with both sides subject to different standards and regulation. This makes it more difficult for people to know how to raise issues and concerns relating to their care, and might enable poor care to go unidentified. Parkinson’s UK strongly supports better integrated care in the community, and believes that there is a case for more effective integration in
terms of regulation. This could be developed alongside the Scottish Government’s ongoing work on community care integration.

**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.

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  
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