



Consultation on Respite Care Guidance Response by the Parkinson's Disease Society in Scotland

Introduction

About Parkinson's

About 10,000 people in Scotland are diagnosed with Parkinson's. It is a progressive fluctuating neurological disorder, which affects all aspects of daily living including talking, walking, swallowing and writing. It is a life-threatening condition that can be managed through specialist care.

Parkinson's affects people from all social and ethnic backgrounds and age groups. Most people are diagnosed over the age of 60. However one in 20 people with Parkinson's are diagnosed before they are 40.

Parkinson's and Carers

A number of factors combine to make the carers of people with Parkinson's specifically vulnerable.

Most people with Parkinson's can expect to have a near-normal life expectancy, which means that their partners and other loved ones often provide care for many years. People with Parkinson's have increasingly complex needs as the condition progresses. Dementia affects 48%¹ to 80%² of people with Parkinson's. Depression is extremely common. Some people with Parkinson's can experience psychotic symptoms and compulsive behaviours.

Because Parkinson's is most common in older people, carers are frequently also older, with personal health issues and disabilities. Many are co-resident.

Appropriate respite services are extremely important for people with Parkinson's and their carers from the point of diagnosis throughout the course of the condition.

The Parkinson's Disease Society is currently undertaking work with its members to increase understanding about the specific needs of carers for people with Parkinson's. This consultation response is informed by themes emerging from this work.

The Society would be glad to explore any of the details of the consultation response in further depth. Please direct any questions or comments to: Tanith Muller, Parliamentary and Campaigns Officer, email tmuller@parkinsons.org.uk , tel: 0141 423 1518.

Summary

The Society welcomes this draft guidance. Good quality, accessible and flexible respite care is an extremely important issue for people with Parkinson's and their carers.

Overall, the guidance demonstrates a good understanding of the issues for service users and carers, and is highly relevant to those affected by Parkinson's.

We would like to highlight the following areas for particular attention:

- The particular challenges of sourcing appropriate respite care within remote and rural communities
- Emergency respite planning
- The importance of quality standards
- The importance of respite provision as a means of reducing the risk of social exclusion amongst carers
- Good practice in cross departmental working
- The need for Scottish local authorities to provide more effective online information for carers
- Recognising and facilitating carers' rights to re-assessment
- Charging for respite as a barrier to accessing services
- Acknowledgement about the impacts of being in multiple vulnerable groups outlined in the guidance
- Definitions of difficulties faced by some vulnerable groups

1. What are the main strengths and weaknesses of the draft guidance?

The main strength of the guidance is that it reflects the issues that service users and carers face in accessing respite care, as well as those affecting service commissioners and providers.

It is also a strength that the guidance reflects the principles and aims set out in the summary: to improve respite planning, with a focus on preventative and personalised support and recognition of the importance of respite for carers.

The Society believes that the Draft Guidance would be further strengthened if the points below were addressed.

2. What is missing?

The Society was surprised that the guidance did not attempt to address the significant challenges relating to respite provision **in remote and rural areas**.

These challenges include:

- isolation from respite centres and other support groups
- transport
- emergency planning
- access to work, training and leisure services
- information for carers

Scotland should be leading the way in provision of flexible, targeted support to carers living in rural areas.

Examples of good practice to address these challenges include:

- the use of direct payments to address carers' needs in innovative ways, such as contributing to the costs of driving lessons or petrol; or for employing a trusted neighbour, who understands the family and therefore the condition, to provide occasional respite care
- information provision online, through GPs, Citizens' Advice Bureaux and other community facilities

The Society welcomes the recognition of the importance of emergency respite (paragraph 23), but the guidance would benefit from specific reference to **planning for emergencies**. Emergency plans should be developed as part of assessment.

It is important that service users and carers know what to do if emergency respite is required. This would include ensuring that the user and carer have emergency contact numbers and have information prepared for the service provider in advance of an emergency.

This is particularly important for people with Parkinson's, as it is a little understood and highly complex condition. Service providers need information about medications management and symptoms to provide appropriate care. This good practice is also applicable to other groups.

Although the guidance refers to the monitoring of **quality standards**, it would benefit from a clear explanation of why high standards are so important and more detail about the type of problems that can undermine users' confidence in the service.

Carers have told the Society that they often lack confidence in the quality of care provided. Common reasons for this lack of confidence include:

- lack of understanding of Parkinson's Disease amongst care home staff
 - absence of stimulating activity whilst in respite care
 - failure to supply medication on time or to facilitate self management.
- Medication management is critical in Parkinson's Disease, and failure to follow the regime exactly can lead to a rapid deterioration in the condition after even a short break

One carer's response is typical: "It's not really a break if they're worst off because of poor respite." Some carers report that people have gone without adequate food and drink due to staff's lack of knowledge about the condition.

A poor experience of respite can prevent people with Parkinson's from taking up opportunities in the future.

The guidance would also benefit from placing greater emphasis on the importance of respite in allowing all carers access to social, education and work-related opportunities under paragraph 5, and recognising the real risks of **social exclusion** for carers in all age groups.

3. Is the terminology clear?

Yes.

4. Strategic Planning - Does the draft guidance cover the most important factors in relation to the strategic planning of respite services?

Yes.

The Society particularly welcomes the recognition of the importance of joint working. However, the draft guidance would be strengthened by inclusion of examples of cross-departmental working in local authorities, for example transport, leisure services and libraries. There are many examples of good practice, including:

- use of mobile libraries to provide carers with information and subsidised DVDs
- travel concessions for carers
- carers' leisure cards

5. Information Provision - Does the guidance cover the main aspects of information provision relating to respite? Are there additional examples of good practice which would be valuable to include?

Information is vital to carers, and the focus on provision of good information is welcome. The Society supports the focus on a proactive approach to information provision and the recognition of the need to target under-represented groups.

However, the draft guidance would benefit from specific reference to online information provision. The Society has recently undertaken a survey of online information for carers provided by 50 randomly selected local authorities across the UK. The survey found that the overall provision of online information for carers was much better in English authorities than in Scotland. For example, none of the Scottish authorities surveyed had a separate information section for carers. On two of the Scottish authority websites the researcher was unable to find any reference to carer's assessments or respite care.

Though not all carers have access to the internet, for many the internet is a valuable source of information, This particularly the case for those who find it difficult to get out of the house, or who live in isolated rural areas. Online provision can also be one of the means of targeting ethnic minority groups.

We strongly welcome the statement that "assessment is the start of an ongoing process, where any service provided is regularly reviewed" (paragraph 31). It is important that carers are made aware not just of their right to assessment, but of their right to reassessment. Carers have told the Society that they are reluctant to access services in the early stages of caring in case this excludes them from relevant services at a later date. This is a particular issue in a progressive condition like Parkinson's where care needs can change significantly over time.

Good practice in information provision includes networking with local voluntary sector organisations, such as local branches of the Parkinson's Disease Society.

6. Eligibility - Are the suggested criteria and risk factors relevant and comprehensive?

The Society welcomes the identification of "at risk" groups in the guidance. As outlined in the introduction, many carers of people with Parkinson's meet several of these criteria.

It is important that the guidance reflects the fact that those people who are in multiple categories are often even more vulnerable.

7. Charging

We particularly welcome the recognition that charging for respite services can deter carers from taking breaks (paragraph 44).

Carers' reports echo the findings of this paragraph. They tell the Society that charges for respite care are a barrier. Those caring for someone with a long-term condition and unable to work may be unwilling to eat into their savings to pay for respite care.

The Society welcomes the acknowledgement that inability to access respite leads to a breakdown in caring relationships and deterioration of carers' own health, both of which increase costs to health and social care services

A minimum 'free' break, available to carers for a maximum period every year, has been used in some areas as ensuring that all carers get a break.

8. Annexe A – Indicators of good respite - Is the list relevant and comprehensive?

The list is relevant and comprehensive, though would benefit from one additional indicator '*Available when needed.*' Carers tell the Society that waiting lists for respite care can be a significant barrier in some areas. Waiting times for aids and adaptations are also a problem.

9. Annexe B – Good practice - Are the examples relevant and useful?

Can you suggest similar examples?

The examples of good practice are very useful.

The Society would add some additional examples:

East Dumbartonshire Council and East Dumbartonshire Community Health Partnership offer joint assessments, with representatives from both health and

social care services. The health needs of carers are taken into consideration during assessment, and this is an excellent example of good practice. The joint assessment also enables a pooling of budgets on shared activities.

Direct Payments can be an important means of enabling carers and users to arrange more flexible respite care that meets their needs. They deserve more than one brief mention in the draft guidance. Their use in rural areas is particularly important and more detailed examples would help to demonstrate their potential.

10. Annex C - Respite needs of specific groups – Again, are those in the draft relevant and useful? Can you provide similar details for the other groups listed? Where possible please provide explanation and examples to support comments

It is very helpful that all of the groups listed are recognised as having particular needs. It is also important to recognise that many carers will fall into more than one of these groups, and that their overall needs will need particular consideration.

For example, carers of people with Parkinson's Disease are more likely to be older carers, co-resident, caring for a long-term progressive condition with the possibility of providing end-of-life care. They face the additional stress related to mental health symptoms associated with Parkinson's. Parkinson's is a disease that can affect anyone, so some carers will also be from ethnic minority groups, or live in remote and rural areas.

Older carers

Particular consideration should be given to the health needs of older carers and regular reassessment should be encouraged. Strategic planning with the local NHS should address issues such as an annual health check for older carers. Emergency planning can be particularly useful for older carers, who will often be concerned about what will happen should they have to go to hospital.

An older couple are also more likely to be in a mutual caring situation, where both support the care needs of the other. This situation is particularly likely where one spouse or partner has been a long-term carer for the other and has developed health problems of their own. Assessment of couples in this situation needs to consider not just the care needs of both individuals but also the combined effect of their caring roles, in order to properly assess their ability to continue caring.

Co-resident carers

Co-resident carers often report that, because they are co-resident, social care staff make assumptions that they will be there to provide the majority of the care and are more likely to ignore the carers' needs, particularly in relation to their wider social life; including work, training and leisure.

Appendix: About the Parkinson's Disease Society

The Parkinson's Disease Society of the United Kingdom (PDS) provides support, advice and information to people with Parkinson's, their carers, families and friends. It also provides 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 nearly £5 million on research into Parkinson's Disease. The Society also develops models of good practice in service provision, such as Parkinson's Disease Nurse Specialists, community support, and campaigns for changes that will improve the lives of people affected by Parkinson's. The Society is not a service provider.

References

- ¹ Hely MA et al. (2005) Sydney Multicenter Study of Parkinson's disease: non-L-doparesponsive problems dominate at 15 years. *Movement Disorders*. **20**(2):190–199.
- ² Aarsland D, et al (2003) Prevalence and characteristics of dementia in Parkinson's disease: an 8 year prospective study. *Archives of Neurology*. **60**:387–392.