

We need to talk about Palliative Care

Parkinson's UK

Introduction

Parkinson's UK strongly welcomes the Committee's Inquiry, and hope that it will help to address inequalities in access to palliative and end of life care in Scotland.

People with advanced Parkinson's report that their quality of life is as bad as – and in some cases is worse than – those with terminal cancer¹ and motor neurone disease (MND).² Yet research shows that people with Parkinson's are very much less likely to have been involved in advance care planning, or to have received specialist palliative care input than those with other types of condition.^{3 4 5} This reflects wider work showing that people with non-malignant conditions are very unlikely to receive specialist palliative care input at all, such as work by Audit Scotland⁶ and Marie Curie.⁷

We are concerned that many people who are dying with advanced Parkinson's in Scotland:

- have not had the opportunity to make informed decisions about their care and treatment in advance
- do not receive the care and support that they need to manage their symptoms effectively, despite the fact that these have a very negative impact on quality of life
- lose contact with Parkinson's specialist teams that have knowledge and skills that may help to relieve some of the difficult symptoms common in very advanced Parkinson's
- receive much of their care in generalist settings such as hospitals and care homes, where staff typically have very limited knowledge about the complexities of managing advanced Parkinson's. They may not have had training in palliative and end of life care, are often under considerable time pressure, and workplace culture may not acknowledge the importance of dealing with dying

¹ Higginson IJ, et al. (2012) Symptoms and Quality of Life in Late Stage Parkinson Syndromes: A Longitudinal Community Study of Predictive Factors. *PLoS ONE* 7(11): e46327.

² Goy ER, Carter J, Ganzini L (2008) Neurologic disease at the end of life: caregiver descriptions of Parkinson disease and amyotrophic lateral sclerosis. *J Palliat Med.* 11(4):548-54

³ Walker RW (2013) Palliative care and end-of-life planning in Parkinson's disease *J Neural Transm* 2013 120:635–638

⁴ Richfield EW et al (2013) Palliative care for Parkinson's disease: A summary of the evidence and future directions *Palliat Med* 2013 27: 805

⁵ Ghoche R (2012) The conceptual framework of palliative care applied to advanced Parkinson's disease *Parkinsonism and Related Disorders* 18 S2eS5

⁶ Audit Scotland. (2008) Review of palliative care services in Scotland.

⁷ Dixon J et al (2015). Equity in Provision of Palliative Care in the UK. LSE, PSSRU, Marie Curie.

There are also considerable issues for carers of people with Parkinson's, who typically have extremely high needs for support because the person can have very significant care requirements which have grown incrementally over many years.

An estimated 5,000 people with Parkinson's in Scotland are living with complex Parkinson's, where their symptoms are challenging and are not effectively managed with medication. As people reach the most advanced stages of Parkinson's their symptoms commonly include pain, fatigue, problems with swallowing, aspiration pneumonia, breathlessness, weight loss, continence issues, frailty, declining physical function, immobility, falls, recurrent infections, weight loss, mental health problems and dementia.^{8 9} It is also common for people with advanced Parkinson's to have very significant side effects from their Parkinson's medication, and to be living with other serious health conditions in addition to their Parkinson's.

The pattern of decline in Parkinson's, as in other neurological conditions and conditions that cause frailty, is different from the typical progression seen in conditions like cancer and organ failure. On average, people live with the most advanced stages of Parkinson's for 2.2 years¹⁰, but this is very variable, and services must be flexible enough to provide appropriate support to people with Parkinson's, their carers, and others close to them throughout the course of the condition as their needs fluctuate and change.

1. What has been your experience in terms of access to palliative and end of life care?

Parkinson's UK is concerned that access to effective palliative and end of life care is often very poor for people with Parkinson's in Scotland.

We would emphasise that our concerns apply to access to palliative and end of life care in each of the following settings:

- care provided within specialist Parkinson's services
- care provided by designated specialists in palliative care (eg in hospices, hospitals and community teams)
- care provided by generalist health and social care professionals in hospitals, care homes and the community

Parkinson's UK believes that all three of these settings must be addressed to improve care and support for people with Parkinson's

⁸ Richfield et al, (2013) Palliative care for Parkinson's disease: A summary of the evidence and future directions *Palliat Med.* 27(9):805-10.

⁹ Higginson IJ, et al. (2012) Symptoms and Quality of Life in Late Stage Parkinson Syndromes: A Longitudinal Community Study of Predictive Factors. *PLoS ONE* 7(11): e46327.

¹⁰ Richfield et al, (2013) Palliative care for Parkinson's disease: A summary of the evidence and future directions *Palliat Med.* 27(9):805-10.

The NICE clinical guideline on Parkinson's¹¹ recommends that people with Parkinson's should have access to palliative care and support from the point of diagnosis onwards. We support this integrated approach to identifying and managing palliative and end of life care needs for people with Parkinson's. This is in line with a broad definition of palliative care, such as the one developed by World Health Organisation:

*"The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with ... treatment."*¹²

The traditional "prognostic" approach may be less appropriate in a long term progressive neurological condition like Parkinson's, which is characterised by unpredictability and fluctuations. It is difficult to establish when a person is reaching the end of life through this model.¹³

Integrated models of care recognise that specialist palliative care can benefit patients from the time of diagnosis, and that palliative needs can fluctuate. Integrated care should be delivered by a person's multi-disciplinary team (MDT) throughout a person's care journey. This requires monitoring and recognition of unmet palliative care needs, identification of triggers for specialist referrals and close working between neurology / medicine for older people and specialist palliative services.

There are some positive models of joint working between Parkinson's services and specialist palliative care teams - for example in NHS Lothian, Parkinson's nurse specialists work closely with colleagues in the community palliative care team, and there are positive relationships with third sector palliative and end of life care providers, such as Marie Curie and local hospices throughout Scotland. However, this provision is not universal and we would like to see Parkinson's teams and palliative care teams resourced to provide more of this kind of support throughout Scotland.

Parkinson's UK is particularly concerned that in many NHS Boards, specialist consultants and nurses are not able to provide ongoing care and support to people when they become too unwell to attend hospital-based clinics. This means that many people with Parkinson's who live in care homes or who are receiving care at home are no longer receiving expert input to help manage their condition.

The crucial role of medication in managing Parkinson's symptoms means that there are particularly complicated decisions about prescribing to achieve the

¹¹ NICE (2006) clinical guideline 35, Parkinson's Disease: Diagnosis and management in primary and secondary care.

¹² World Health Organisation (1990) Cancer pain relief and palliative care. Technical report series 804. Geneva: WHO.

¹³ Richfield et al, (2013) Palliative care for Parkinson's disease: A summary of the evidence and future directions *Palliat Med.* 27(9):805-10.

best possible outcomes for each individual. This is best achieved by specialist professionals with an in depth knowledge of Parkinson's. There are pockets of excellent practice across Scotland, for example the Parkinson's team in Edinburgh is now running inreach to local care home residents with Parkinson's, and in Aberdeen Parkinson's nurses are also undertaking regular care home visits. In the Western Isles, the Parkinson's nurse undertakes home visits. In some parts of the country, Parkinson's nurses have excellent relationships with community palliative care teams and other community teams and provide more arms-length support.

Sandy, from Inverness, explained the difference that support from his Parkinson's nurse Sharon, and consultant made when his wife Loes was reaching the end of her life:

“Loes had a mixture of serious physical and mental health symptoms, which meant her care needed to be really well co-ordinated.... Sharon and the consultant Dr Wilson adjusted treatment to minimise her symptoms and medication side effects. I would email Sharon with any changes that concerned me and she would let me know if these were significant, and would involve Dr Wilson if they were serious. I feel strongly that this personal contact meant that Loes received the best possible medical treatment.

“It gave me confidence to have as positive an attitude as possible. I always felt there was a way to do things. We even managed to attend her son's wedding in Salzburg the September before she died. She was also able to see both her grandsons, and we celebrated her 60th birthday with all her family.

“The end of life stage was very hard, but it was handled as well as it could have been. Thanks to Sharon, I didn't have to face difficult information and decisions on my own. I am so grateful that she was able to sit with Loes immediately after I was told that she was entering the final phase of her life. Sharon and Dr Wilson worked alongside our GP practice, so Loes was able to die peacefully at home surrounded by her family. That meant so much to all of us.”

Research in Scottish general practices shows that people reaching the end of life with non-malignant conditions are very much less likely to be included on GPs' palliative care registers. This makes it much harder to access care packages and may mean that key information is not shared if a person requires emergency care. GPs reported that they were less comfortable placing people who did not have cancer on the register. Reasons included uncertainty of prognostication, reluctance to include people on the register for longer than a year, and some concern that the register was only really of use to people with cancer.¹⁴ Parkinson's UK is concerned about whether the rollout of the Key Information Summary (KIS) will show similar issues.

¹⁴ Harrison, N. et al (2012). Are UK primary care teams formally identifying patients for palliative care before they die?. *British Journal of General Practice*, 62(598), e344-e352.

We believe that people with advanced Parkinson's need to be identified on such registers. It is essential that the information enables health and care professionals to distinguish between cases where people can benefit from a treatment or hospital admission (despite having complex condition and reaching the end of life) and those where interventions and hospital admissions are best avoided. Sharing information through systems like KIS is also essential to make sure that advance care planning information is shared with all the health and care staff who need to know a person's wishes.

Data from England show that fewer than one in ten people with Parkinson's mentioned on their death certificates die at home,¹⁵ and we expect that the pattern is similar in Scotland. Most people dying with advanced Parkinson's do so in general hospitals and care homes, and the experiences of people dying with Parkinson's and those closest to them is very varied. In a study from northeast England 47% of people dying with Parkinson's died in hospital. Only three patients, and seven relatives of patients, had recorded a discussion with a clinician about their preferred place of death and only 14% were referred to a specialist palliative care team.¹⁶

People with advanced Parkinson's are at very high risk of hospital admission. When they are in hospital, it is critical that they receive their Parkinson's medication at the correct time and the correct dose. If they don't, symptoms and side effects can become uncontrolled, and this is dangerous and extremely distressing. We are aware of situations in Scotland where relatives have been summoned to the bedside of someone who was thought to be dying, when in fact their deteriorating condition was caused by missed Parkinson's medication.

We have heard stories of excellent person-centred care in care homes with excellent symptom management and a commitment to enable clients to die in a familiar place. But we have also heard horror stories about pain medication regularly being missed leaving a resident in severe pain, or people not receiving their essential Parkinson's medication on time or at the correct dose with an appalling impact on the person's health and wellbeing.

It is extremely important that general hospital staff and care home staff recognise, and have the confidence, skills and time to provide care and support for people who are dying, their carers and others close to them. Parkinson's UK believes that palliative and end of life care needs to be seen as "everyone's job", with health and social care workers in all settings taking responsibility for providing good end of life care, being sensitive to – and transparent about - issues around the end of life end enabling people's wishes to be known and acted upon. In addition, it is essential that general staff and specialist palliative care teams alike have ongoing contact with Parkinson's specialists..

¹⁵ End of life care intelligence network (2010) [Deaths from Neurodegenerative Diseases in England, 2002 to 2008'](#)

¹⁶ Walker, RW et AL (2014) Palliative care in people with idiopathic Parkinson's disease who die in hospital *BMJ Support Palliat Care* doi:10.1136/.

2. How could it be ensured that access to palliative and end of life care is equitable and available in all areas and for all types of terminal illnesses?

The restriction of palliative and end of life care to people with a terminal illness is one of the major reasons for a lack of access to this support for people with Parkinson's. Parkinson's is not typically defined as a terminal condition, and people with advanced Parkinson's find it impossible to access services and benefits that depend on a time-based prognosis because the progression of Parkinson's is unpredictable.

People with advanced Parkinson's typically have both physical disability and dementia, and not all specialist palliative and end of life care services feel able to support people with complex needs.

Parkinson's UK believes that it is essential to ensure that palliative and end of life care is offered to people with non-malignant diseases. However this will require developments in practice because so much of the expertise in specialist palliative care services has grown up around the treatment of malignant disease, and while some knowledge and skills may be directly transferable, others will not. There are also cultural issues as often the professional and public perception is that palliative care is only suitable for people with cancer.

Parkinson's UK believes that health and social care integration provides a real opportunity for specialist palliative care teams to build relationships with generalist colleagues across health and social care sector, to enable knowledge and skills to be shared across settings. However, we would emphasise that there remains a need for skilling and cultural shift in acute hospital specialities which may not be subject to integration.

Parkinson's UK also notes that key Scottish Government policies such as the 2020 Vision for Health and Social Care do not mention these issues. We believe that death, dying and bereavement must be mentioned in future health and care policy to ensure that the culture of health and social care acknowledges that death and dying are "core business" and are not always preventable.

3. Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?

Parkinson's UK believes that the biggest priority in terms of access to palliative and end of life care is non-malignant conditions, and in particular to progressive neurological conditions.

Parkinson's UK would also prioritise:

- developing practice in supporting people with dementia and / or communication issues. People dying with advanced Parkinson's commonly have both dementia and issues with speech, and cannot communicate symptoms like pain (which is common and often severe),

or articulate what would bring them greater feelings of wellbeing. In one recent study 89% of people with Parkinson's experienced pain.¹⁷ But people with dementia can find it hard to communicate pain, and their carers need training to recognise it.¹⁸ We are concerned that many people with Parkinson's may not be receiving the pain relief that they need.

- the upskilling of generalist health and social care staff in palliative and end of life care issues, so that they are better able to support individuals with life limiting conditions and those close to them
- the shortage of social care packages must be addressed. We are aware of people who have died at home without social care support, despite being assessed a year earlier, and situations where unpaid carers have taken on the care of people with very advanced Parkinson's despite the fact that essential care packages are not in place, in order to have them "at home"
- systems to make sure that people have opportunities to engage in advance care planning at every stage, that this information is recorded and shared so that all professionals have access to it
- addressing the fact that there is very limited data about the provision and accessibility of palliative and end of life care in Scotland , especially in comparison with England. It is impossible to measure progress if information is not collected or analysed

4, When is the right time to begin discussing options for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?

As outlined above, Parkinson's UK advocates an integrated approach to palliative care that begins from the point of diagnosis. Ideally, all discussions would involve the person with Parkinson's, carers or those closest to them, their Parkinson's multi-disciplinary team, GP and any health or social care workers engaged in providing care. Where discussions take place, decisions must be documented and shared.

The risk of dementia is particularly relevant in terms of encouraging early conversations. People with Parkinson's have a significantly increased risk of developing dementia - between 4 and 6 times higher than people of the same age without Parkinson's. Up to 80% of people who have lived with Parkinson's for more than a decade will develop dementia.¹⁹ Given the high risk of losing mental capacity, people with Parkinson's should have an opportunity to

¹⁷ Kass-Iliyya L et al (2015) Pain in multiple system atrophy and progressive supranuclear palsy compared to Parkinson's disease. *Brain Behav.*5(5):e00320.

¹⁸ <http://www.scie.org.uk/publications/dementia/advanced-dementia-and-end-of-life-care/end-of-life-care/files/pain-in-advanced-dementia.pdf?res=true>

¹⁹ Perez F et al, (2012) Risk of dementia in an elderly population of Parkinson's disease patients: A 15-year population-based study *Alzheimers Dement.* 8(6):463-9

express their priorities and preferences and make plans as soon after diagnosis as they want to. Specialist consultants and / or Parkinson's nurses should offer regular opportunities to discuss these issues.

Parkinson's UK believes that where someone with Parkinson's initiates a conversation about palliative and end of life care, health professionals need to be prepared to have that conversation. Similarly, where a person does not wish to discuss these issues, it is essential that health and care professionals respect this decision.

These conversations often take place informally between individuals and those closest to them. We believe that health and care professionals need to be prepared to treat carers and others close to the person as partners in care. They can help professionals to understand a person's wishes, even where they do not have legal rights to make care decisions on behalf of an individual. Although Parkinson's UK strongly advocates the use of Powers of Attorney, we also recognise that the uptake remains very low in Scotland, with only about 55,000 POAs in place. We believe that health and care professionals in all settings need to have an understanding of the Adults with Incapacity Act and related legislation. However, teams also need to work in difficult situations where legal provision has not been made.

6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?

Parkinson's specialist nurses in Scotland report that it has become easier to support people with advanced Parkinson's to receive appropriate care at the end of life over the last few years because of the work that has been done to embed advance care planning in NHS Boards. Parkinson's UK is currently auditing Parkinson's services in Scotland and across the UK to identify how many people are being given the opportunity to take up advance care planning.

Parkinson's UK