

## **Executive summary**

### **Exploring the palliative care needs of service users with neurological conditions**

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## **Study overview**

The project took place between October 2006 and September 2008 and focused on providing data to inform recommendations for best practice and insights into the applicability of interventions to enhance palliative and end of life care within this client group.

## **Study aims**

The study had three key aims:

- To understand the evidence base and challenges of delivering palliative and end of life care in neurological care;
- To understand service users' and informal carers' expectations and experiences of care in particular health care environments;
- To describe the outcomes of care for people dying with neurological conditions in particular health care environments.

## **Study design.**

We used a mixed methods design to gather a range of perspectives on palliative and end of life care delivery and outcomes. We engaged service users (n=6), family carers (both current (n=48) and bereaved carers (n=7)) and health and social care professionals (n=82<sup>1</sup>) in interviews, focus groups or via a questionnaire survey. In addition, the notes of 37 service users who died between January 2005 and December 2006 were audited, to gain insight into issues relating to their care in the last four weeks of life. In total, we included 180 individuals or their records in the study.

## **Study settings**

The study took place across three sites:

- Six Sue Ryder Care neurological centres
- St Joseph's Hospice, London
- National Hospital for Neurology and Neurosurgery, London

## **Findings**

### *Staff perspectives*

Findings show that there is limited literature on the psychosocial aspects of living with and caring for people with progressive long-term neurological conditions, particularly Huntington's disease. Discussion with staff providing care to those with progressive long-term neurological conditions identified that they value a multidisciplinary approach and actively draw on each others expertise. Staff perceived that developing relationships with service users was important to establish information about their wishes and care needs thus informing end of life care.

Continuity of staffing was a key element for both staff and family carers; getting to know the patient was reported to be of key importance in delivering appropriate care to that individual. Developing expertise in the provision of end of life care was perceived by staff across all sites as challenging as deaths from progressive long term conditions do not often occur. Staff commented on having to 'relearn' elements of delivering good end of life care on the occasions they cared for someone who died.

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<sup>1</sup> 80 in interviews or focus groups, plus two in service user case studies.

Staff also identified some challenges for the delivery of palliative and end of life care including: variable support from community health and social care professionals; organisational constraints; funding and access to wider services for patients. For staff working in long term care centres, limited in-house medical and nursing provision placed a constraint on the level care that could be delivered at the centre.

#### *Perspectives of service users and their families*

For both service users and their families, moving to residential care is a significant and difficult adjustment. However the safety and security of long-term care was valued. In time, staff often became regarded as friends or second family. Service users prefer to focus on the ‘here and now’ and maintaining their current level of health and activities rather than contemplating the future. Interviews with family carers and a survey of quality of life among family carers of people with Huntington’s disease demonstrated how caring for someone with a neurological condition has implications and consequences for the whole family. In spite of these difficulties, handing over care to professionals and transition to a new role is a difficult experience for family carers.

Family carers found that, although difficult, learning about their relatives’ wishes for future care was important since it provided a guide to end of life decision-making once the service user could no longer participate in decision making. Both staff and relatives recognised it was not always possible to have a planned death and had similar views about what made a ‘good death’.

#### *An audit of documentation relating to the last four weeks of life*

The audit of care in the last four weeks of life demonstrated that there is little recording of advance discussions about care or of expressed wishes for care at the end of life. Preferred place of care was not often noted. ‘Do not attempt resuscitation’ orders were sometimes recorded but often with no information about the way in which this decision had been made, the extent of the any discussion, who was present, or when the decision should be reviewed. It became clear that the level of recording did not adequately reflect the actual level or extent of discussions taking place with service users and their families. It should be noted that our study took place before adjustments to record keeping had been made in the light of the Mental Capacity Act.

## **Conclusion**

The numbers of people living with long term conditions, including neurological conditions, will continue to increase over the course of the next decades. Taking a palliative care approach to the organisation, delivery and conceptualisation of care is necessary in order to respond to the wide ranging and complex needs of service users and their families, which often extend over many years. This study, which was primarily a study of a key provider of neurological care-Sue Ryder Care- has drawn on the experiences of over 100 staff, service users and family members to compile a detailed picture of the challenges, opportunities and outcomes of palliative focused care in this field. We hope it will generate discussion aimed at the development of recommendations to further develop practice, education and research for the benefit of all those affected by long term neurological conditions.