

# Palliative care in neurology

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## Abstract

Palliative care is a very important part of the care for people with neurological disease, and their families. This may be appropriate in any patient group, but is particularly helpful for patients with progressive neurological disease and when the disease is progressing towards the end of life. A multidisciplinary approach allows the assessment and management of the various issues facing patients – physical, such as symptom management, psychological, social and spiritual. In this way the quality of life of patients can be maintained and preparations made for the end of life, so that they are able to have their symptoms managed effectively and die peacefully.

## Introduction

Although palliative care has often been associated with the care of people with cancer there has been increasing awareness of neurological palliative care and in 2016 the European Academy of Neurology and the European Association for Palliative Care collaborated in producing a Consensus document<sup>1</sup>. This document emphasises the increasing importance of palliative care for neurological patients, and their families, and the need for neurologists to become involved.

Palliative care is defined by the World Health Organisation as “An approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”<sup>2</sup>. Thus, neurologists are very closely involved in providing palliative care as many patients do have a life-threatening illness – this may be a progressive disease such as motor neurone disease (MND) or in acute situations when death may occur suddenly, such as in acute stroke or infections. In all patient care it is important to ensure good communication with patient and family, share decision making and goal setting and provide symptom management. Specialist palliative care may be needed for some more complex patients, where the team would provide palliative care as their main activity and have received specialist training and continuing education<sup>3</sup>.

## Palliative care assessment

The assessment of the patient and family will involve all aspects of care, as described in the WHO Definition:

- Physical – the various symptoms that may be experienced by the patient, including pain, breathlessness, dysphagia, dysarthria, mobility issues, tremor, confusion, agitation, anxiety, depression. There is a need to be proactive in looking for symptoms, as patients and families may be reluctant to talk about some issues. The careful elucidation of the cause of the symptom is essential before treatment – which may be using medication or non-pharmacological<sup>1</sup>.

The assessment may need to be of mobility and positioning, as the patient becomes less mobile and more dependent, and the wider multidisciplinary team should be involved.

- Psychological – patients will have their own concerns about their diagnosis, disease progression or their future. This may present as anxiety or depression, but other issues may need to be heard and addressed appropriately.
- Social – most people are part of larger family groups, who will have their own particular concerns and for whom the patients may have concerns. It is important that these issues are heard and support given.
- Spiritual – patients may have specific religious concerns but more often may express their worries about the future, or issues related to their illness – such as “why me?”, “how will I cope”, “what happens as I am dying or after death”<sup>4</sup>. These may be openly expressed or discussed in less obvious ways, as concerns about other aspects of life. The wider multidisciplinary team may be able to respond and support the person and their family and allow expression of these issues.

This assessment of all of the issues that are important to the person, and their family, will often involve the wider multidisciplinary team. It is important that the team members liaise and can involve other members of the team appropriately.

## Effectiveness of palliative care

There is increasing evidence for the effectiveness of palliative care, although this is limited. A Cochrane

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Library Systematic review of 23 studies that evaluated home palliative care for people with advanced illness did show that people were more likely to die at home and there was evidence that symptom burden was reduced<sup>5</sup>. A similar Cochrane Review of palliative care interventions for people with multiple sclerosis (MS) showed no clear evidence of any effect on quality of life or hospital admissions<sup>6</sup>. Within cancer care there has been evidence that early palliative care involvement improves quality of life and mood and length of survival<sup>7</sup>.

There have been studies looking at the effectiveness of palliative care for people with neurological disease. A short-term palliative care intervention was found to lead to improvement of symptoms for people with MS, whereas the control group deteriorated, and this was associated with improvement in caregiver burden and was found to be cost effective<sup>8,9</sup>. The provision of extra training in palliative care for specialist MS nurses was shown to help in symptom management but did not affect quality of life or other outcomes<sup>10</sup>. A randomized controlled trial of multidisciplinary palliative care for people with advanced neurological disease, including MND, MS and Parkinson's disease (PD), found an improvement in quality of life and symptoms – pain control, breathlessness, sleep disorders and bowel symptoms – and there were trends for improvement in other symptoms<sup>11</sup>.

There is also increasing evidence for the effectiveness of multidisciplinary team (MDT) care. Within the care of MND two studies have shown that the MDT approach may lead to an increase in length of life<sup>12,13</sup>. It is unclear as to the most important aspect of the MDT approach but it may be due to the closer working relationships, the development of trust between team members and the ability of close collaboration and sharing of information. This may be partly supported by the evidence on neurological palliative care where the involvement of a wider multidisciplinary team on an intensive basis, with regular visits and support<sup>11</sup>, was more effective than a short-term intervention<sup>8,10</sup>.

A multidisciplinary palliative care out-patient clinic for people with PD has been shown to improve quality of life, non-motor symptoms, the severity of motor symptoms and the completion of advance care planning documents<sup>14</sup>. There were improvements in caregiver anxiety and care giver burden but these were only significant after 12 months and were less conclusive. There was also evidence that the benefits were greater for people who were found to have a higher level of palliative care needs<sup>14</sup>.

### Care at the end of life

Although palliative care may be appropriate, according to the needs of the patient and family, at any time during the disease progression there is a particular

need to ensure that a full assessment is undertaken as the person becomes iller and approaches the final stages of their illness. It has been suggested that there are certain triggers that may indicate that the end of life, the last 6 to 12 months, is approaching. These are swallowing problems, recurring infection (especially aspiration pneumonia), marked decline in functional status, first episode of aspiration pneumonia, cognitive difficulties, weight loss and significant complex symptoms, as well as the overall impression of the professional team<sup>15</sup>. Although these were initially decided by consensus within a group of experts, a retrospective survey of patients who had died with neurological disease showed that the number of triggers increased as death approached<sup>16</sup>. A particularly significant trigger was aspiration pneumonia which was seen primarily in the last 6 months of life and may reflect a patient who is deteriorating, with reduced generalised weakness, poor swallowing, reduced cough and increased breathing issues.

The recognition of the end of life phase is important as it allows the multidisciplinary team to focus particularly on symptoms, other physical issues and psycho-social concerns, and facilitate communication with the patient, if this is possible, the family and all the professionals involved in the person's care. In this way potential crises may be anticipated and plans made to ensure that the patient's wishes are met. There is also the opportunity for all involved to discuss the situation and be more prepared for the death. It is particularly important for the family to become more aware, together with the patient, if they are able to be involved in these conversations.

As the disease progresses and death approaches careful consideration should be given to medication. There may be existing medications that are no longer appropriate, such as statins, which may be stopped. Medication may need to be prescribed so it is readily available to cope with new anticipated symptoms. For instance, for a patient at home it is important to ensure that medication is in the home to cope with pain, choking, breathlessness or distress is important – often an analgesic, anti-emetic, a relaxant and an anticholinergic, to reduce chest secretions. If these are readily available any professional can administer them or on occasions, with training, the family may be able to give the medication and minimise distress at the end of life.

As patients with neurological disease deteriorate, they may face reduced communication and / or cognition. Thus, advance care planning (ACP) is particularly important when a person, while they have capacity to make decisions, expresses their wishes about the treatment they would wish to receive or not receive if they lose capacity – due to cognitive changes, loss of communication or severe weakness or loss of consciousness<sup>17</sup>. This may be as a specific Advance Directive, where the

person states the treatments they do not wish to receive, or the appointment of a proxy, or advocate, to make decisions on their behalf if they lose capacity – the professionals may ask the proxy for their view of the person's wishes. In these ways the person, who has lost capacity is able to influence the care they receive and this is often reassuring for the patient and relieves the burden from family<sup>1</sup>.

## Conclusion

Palliative care should be available according to need, rather than just restricted to a specific period towards the end of life. The needs of patients will vary over time and palliative care may be appropriate at certain times. For instance, a patient with MND may have greater palliative care needs at diagnosis, as they face the challenge of coping with the disease and the fears it may engender, when gastrostomy is considered, when respiratory support is discussed and towards the end of life. This may, for many patients with MND, be over a period of two to three years, although for some it may be over a longer timescale. A person with PD may have similar varying needs, perhaps related to pain, non-motor symptoms, disability, aspiration pneumonia and in the later stages of the disease progression, but this may be over 10 to 15 years, or even longer. Specialist palliative care or hospice care may be needed at any time if these needs are more complex and the specialist MDT may provide other care during the periods between this involvement.

There is a need for all involved in the care of neurological patients and their families to increase their skills – for neurologists to learn more about the management of symptoms and palliative care and for palliative care specialists to understand more about the issues for neurological patients<sup>1</sup>. In this way there can be greater collaboration and interaction between teams and improved care for patients and families. In Europe a EAN / EAPC online survey found that there was often collaboration between neurology and palliative care for people with MND and brain tumours and less often with MS and PD<sup>18</sup>. The level of collaboration varied greatly, from occasional contacts to joint clinics.

Discussions about care at the end of life may take place throughout the disease progression whenever patients and families would like to do so and particularly at times when decisions are made about future management, including diagnosis or if interventions are being considered, such as gastrostomy or non-invasive ventilation<sup>1</sup>.

There is discussion of the role of the neurologist as a palliative care provider<sup>19</sup> and that the role of the neurologists is changing from being purely a diagnostician to the provision of ongoing care for patients and

their families, sharing in their growth and decline, and supporting them in their deterioration and later stage<sup>20</sup>. This will encompass primary palliative care – discussing serious news, managing symptoms, ensuring treatment is aligned to the patients' wishes, preparing for end of life and working as part of the wider multidisciplinary team.

This is a challenge for the future but palliative care and neurology need to collaborate, so that the quality of life of patients, and their families, can be maintained at as good a level as possible and enabling them to die peacefully.

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