

# Palliative care in chronic and progressive neurological disease: summary of a consensus review

A taskforce of the European Association for Palliative Care has worked with the European Academy of Neurology to produce a consensus review on palliative care in neurological disorders, which was published in the *European Journal of Neurology* in January 2016. **David Oliver, Gian Domenico Borasio, Augusto Caraceni, Marianne de Visser, Wolfgang Grisold, Stefan Lorenzl, Simone Veronese and Raymond Voltz** outline the main recommendations

**M**any people with neurological disease need palliative care. The role of palliative care for those with progressive disease – such as amyotrophic lateral sclerosis (ALS)/motor neurone disease (MND), Huntington's disease, Parkinson's disease (PD), the associated progressive supranuclear palsy and multiple systems atrophy, and multiple sclerosis (MS) – has already been delineated, although prognosis and the timing of palliative care involvement will vary.<sup>1,2</sup> Patients with other neurological conditions, such as stroke, brain injury and brain tumours, may also benefit from palliative care and, in many parts of Europe, are cared for by neurology services.

## Key points

- The role of palliative care for people with progressive neurological disease – such as motor neurone disease, Parkinson's disease and multiple sclerosis – has already been delineated. Patients with other neurological conditions – such as stroke, brain injury and brain tumours – may also benefit from palliative care.
- In collaboration with the European Academy of Neurology, a taskforce of the European Association for Palliative Care has produced a consensus review on the development of palliative care for people with chronic and progressive neurological disease.
- It makes recommendations on the early integration of palliative care, multidisciplinary team care, communication, symptom management, carer support, end-of-life care – including the wish for hastened death – and training and education of professionals.
- This consensus review will hopefully be followed by further collaboration aimed at increasing the evidence base and include palliative care in all services for neurology patients.

A taskforce of the European Association for Palliative Care (EAPC) has been working in collaboration with European neurological societies – initially the European Federation of Neurological Societies and, following its amalgamation with the European Neurological Society, with the European Academy of Neurology (EAN). This collaboration has produced a consensus review on the development of palliative care for patients with chronic and progressive neurological disease, which was published in the *European Journal of Neurology* in January 2016.<sup>3</sup>

This article is a summary outlining the main recommendations from the consensus review.

## Consensus review

To produce the consensus review, a widespread literature search was undertaken and repeated several times over a number of years. This thorough search yielded 964 publications and, from these, 68 studies were selected to be included in the review. Initially we had planned to produce guidelines, but we found that the evidence on palliative care in neurological disease was too limited, so we agreed to work on a consensus review instead.

The evidence was derived from the included papers using a grounded theory approach. Two of the investigators looked at the literature and then shared the evidence they had found with the other authors. The evidence was discussed and graded A (established as effective), B (probably effective) or C (possibly effective).<sup>4</sup> Finally, recommendations were agreed. More information about how the

**Box 1.**  
**Consensus review**  
**recommendations**  
**on palliative care**  
**in neurological**  
**disease<sup>3</sup>**

### Early integration of palliative care

- Palliative care should be considered early in the disease trajectory, its timing depending on the underlying diagnosis (evidence level C)

### Multidisciplinary team

- Assessment and care of patients should be provided by a multidisciplinary team consisting of at least three different professions: physicians, nurses and social workers or psychologists/counsellors (evidence level C)
- Patients should have a multidisciplinary palliative care assessment and access to specialist palliative care for ongoing management (evidence level B)

### Communication

- Communication with patients and families should be open and include the setting of goals and discussion of therapy options. It should be structured following validated models (evidence level C)
- Early advance care planning is strongly recommended, especially when impaired communication and cognitive deterioration are likely to occur as disease progresses (evidence level C)

### Symptom management

- Physical symptoms require thorough differential diagnosis, pharmacological and non-pharmacological management and regular review (good practice point)
- Proactive assessment of physical and psychosocial issues is recommended to reduce the intensity, frequency and need for crisis intervention and unplanned care (evidence level B)
- The principles of symptom management inherent to palliative care should be applied to neurological care (evidence level B)

### Carer support

- The needs of carers should be assessed on a regular basis (evidence level C)
- Supporting carers – before and after death – is an indispensable part of palliative care, as it may reduce complicated grief and improve carers' quality of life (evidence level C)
- Professionals involved in the care of patients with progressive neurological disease should receive education, support and supervision to reduce the risks of emotional exhaustion and burnout (evidence level C)

### End-of-life care

- Ongoing, regular discussions with patients are essential because their physical and cognitive function, as well as their preferences, will change over time (evidence level C)
- Professionals should encourage open discussions about the dying process and explain that, with appropriate care, most patients will die peacefully (evidence level C)
- Professionals should encourage open and regular discussions of patients' wishes to restrict treatment and interventions, as well as their wishes for hastened death (evidence level C)
- Recognising deterioration that may indicate that patients are in their last weeks and months of life is important for appropriate management (evidence level C)
- Diagnosing the start of the dying phase, although it may not always be possible, is important for appropriate management, including the use of appropriate medications and interventions, and the care and support of families (evidence level C)

### Training and education

- Palliative care principles should be included in the training and continuing education of neurologists (good practice point)
- The understanding and management of symptoms experienced by patients in the advanced stages of neurological disease should be included in the training and continuing education of specialist palliative care professionals (good practice point)

consensus review was produced can be found in the *European Journal of Neurology*.<sup>3</sup> The recommendations are outlined in Box 1 and briefly explained below.

## Overview of recommendations

### Early integration of palliative care

There is increasing evidence of the effectiveness of palliative care and the multidisciplinary

approach in cancer settings.<sup>5,6</sup> There are studies showing that they can also improve quality of life and alleviate some of the symptoms experienced by patients with neurological conditions.<sup>7-9</sup> The timing of palliative care involvement will vary; in ALS/MND, for example, the average prognosis is two to five years, so it may be appropriate to start palliative care soon after diagnosis, whereas in PD the

average prognosis is 15 years, so the palliative care team may not get involved until much later in the disease trajectory.

### **Multidisciplinary team**

The authors of the consensus review defined the multidisciplinary team as one where each member contributes their expertise and works in close collaboration with all other members. At least the following three professions should be represented on the team:

- physicians
- nurses
- social workers or counsellors/psychologists.

The team may also include other professionals: physiotherapists, occupational therapists, dietitians and speech and language therapists. There is increasing evidence of the effectiveness of the multidisciplinary approach, particularly in the care of people with ALS/MND<sup>10-12</sup> and MS,<sup>7</sup> with increased satisfaction with care and length of survival.

### **Communication**

The importance of communication with patients and families is familiar to those working in palliative care, and there have been many studies showing that clear communication improves the care of people with progressive disease.<sup>13</sup> There

is less evidence from within neurological care, and issues around communication may be a challenge for neurology services, which need to increase awareness and improve education among staff.

### **Symptom management**

So far evidence that palliative care relieves symptoms and improves the quality of life of people with neurological disease has been limited, but it is increasing. One study of people with ALS, MS and PD showed an improvement in quality of life and a decrease in pain, dyspnoea, sleep disturbances and bowel symptoms.<sup>9</sup> Further studies are currently being conducted. Also, there is evidence from other disease areas that palliative care improves both quality of life and survival.<sup>6</sup>

### **Carer support**

Palliative care should include the assessment of all aspects of a patient's care, including psychological and social aspects. There is

evidence that assessing carers' needs and providing support to them reduces carers' burden and mitigates the negative effects of long-term caring.<sup>14,15</sup> Carers may find it particularly difficult to cope when the person they care for undergoes cognitive change, which is likely to occur in the later stages of many neurological diseases.<sup>16</sup> Carers will also need support after the person's death,<sup>17</sup> and support should also be given to the extended family.

Professionals may also feel increasingly burdened, particularly when they are working in a caring role for prolonged periods of time and confronted with increasing physical dependency and cognitive change in their patients.<sup>18</sup> Professionals also face continual loss and may develop feelings of meaninglessness and helplessness. Appropriate advice, training and support may reduce the risks of burnout and emotional distress.<sup>19</sup>

### **End-of-life care**

There is increasing evidence that the end-of-life phase can be recognised through assessment and monitoring of signs such as swallowing problems, recurring infection, aspiration pneumonia, marked decline in function, cognitive difficulties, weight loss and increasing complexity of symptoms.<sup>20-22</sup> This is important, as diagnosing the terminal phase can help patients, families and professional carers plan appropriate symptom management and psychosocial support, and be better prepared for the death.

Many people with neurological disease fear distress and pain in the dying phase, and some will want to discuss hastening their own death, whether through euthanasia or physician-assisted suicide.<sup>23,24</sup> In the Netherlands, up to 31% of people with ALS consider hastened death and 69% of those follow this through.<sup>25</sup> Patients and families should be allowed to talk about their fears, concerns and wishes. Support and advice on how to manage physical symptoms and/or emotional distress are often helpful.

### **Training and education**

Neurology teams may receive little education in palliative care principles and how to break bad news. Conversely, palliative care services may have limited knowledge of the specific issues arising in neurological disease, and of the availability and effectiveness of interventions

## **Neurology teams may receive little education in palliative care principles**

and medications.<sup>26</sup> All professionals looking after patients with complex needs, particularly patients with variable levels of cognition, need training in communication skills.<sup>27</sup> Training and education of all those involved is, therefore, essential and must extend both to professionals in training and those in continuing medical education.

## Conclusion

Although it is often limited, there is evidence that palliative care and increased support for patients with neurological disease and their families leads to improved care and better patient experience. There is a continuing need to develop the evidence base and ensure that palliative care is included in guidelines about the care of people with neurological disease. This is already the case for ALS,<sup>28</sup> but needs to be done for other neurological conditions.

With the publication of this consensus review, the EAPC Taskforce on Palliative Care for People with Neurological Disease has completed its work. Working on the consensus review has created links between the EAPC and the EAN, and we hope to continue this collaboration for the benefit of patients, families and professionals.

**Declaration of interest**  
None declared.

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