

Palliative Care in Neurology

In a collaborative effort together with The European Association for Palliative Care and the European Federation of Neurological Societies this ARG is involved in producing guidelines on palliative care of neurological disease and a core curriculum for neurology and palliative medicine.

These guidelines are aimed at encouraging collaborative working between neurology and specialist palliative care services to improve the care of people with neurological disease. The guidelines are being developed from a literature search of relevant articles and using a group of experienced clinicians and researchers in both palliative care and neurology to determine areas for the guidelines agree relevant supporting evidence for recommendations and grade the evidence using the GRADE system.

The following areas of recommendations have been suggested:

- Palliative care should be considered early in the disease trajectory
- Assessment of care should be by a multidisciplinary team
- Patients should have access to a palliative care assessment
- Communication with patients and families should be open, including setting of goals and therapy options
- Early advance care planning is recommended
- Recognition of deterioration over the last weeks and months is relevant for appropriate management
- Proactive assessment of physical and psycho-social issues reduces the need for crisis intervention
- The principles of symptom management should be applied to neurology
- Diagnosis of the dying phase allows appropriate management and standardised tools, such as the Liverpool care of The Dying patients may be helpful
- Carers needs should be assessed regularly and support provided – before and after death
- Professionals should receive support and supervision
- Palliative care principles should be provided in the training and education of neurologists
- The understanding and management of neurological symptoms should be provided for specialist palliative care professionals

The guidelines are being written at present and it is hoped that they will be available for the EFNS Congress in Stockholm in September 2012, the EAPC Congress in Prague in early 2013 as well as for the Vienna WFN congress in September 2013.

The group consists of about 15 international members, more always welcome, and tries to present teaching modules to the WFN congresses, such as in Marocco in November 2011.