Palliative neurology: early start, multidisciplinary approach

Palliative medicine goes far beyond the treatment of people suffering from terminal cancer. It is precisely patients with incurable neurological diseases who can benefit enormously from early multidisciplinary palliative care. These views were expressed by experts at the Congress of the European Academy of Neurology in Amsterdam.

Amsterdam, 25 June 2017 – In large parts of the population, palliative care is generally equated with the care of terminal cancer patients. “This concept of care alleviates symptoms and helps to retain quality of life. However, its significance goes far beyond the end-of-life care for cancer,” explained Prof David Oliver from the University of Kent in Canterbury, Co-Chair of the Scientific Panel on Palliative Care of the European Academy of Neurology (EAN). The WHO definition of palliative care talks for good reason about a “life-threatening disease” in a very general sense and not just about cancer care. Prof Oliver: “Palliative care in neurology can be helpful to patients and their families even much earlier in the disease process, with certain diseases even from the time at which the diagnosis is made.”

Great need for palliative care in neurology

It is precisely neurological diseases that are often accompanied by serious and impairing symptoms so there is a great need for palliative care. Prof Oliver: “There are many progressive neurological diseases we cannot cure. At best, we can slow down their progression. Care based on palliative concepts can greatly contribute to patients’ ability to cope better with their symptoms and problems.” This applies not just to patients with multiple sclerosis, multisystem atrophy, amyotrophic lateral sclerosis and other degenerative impairments of the nervous system but also, for instance, to sufferers of dementia, Huntington’s or Parkinson’s disease as well as to patients living with the consequences of severe strokes, encephalitis or brain tumors.

Consensus Review summarizing the evidence

The ideas about what cancer patients need beyond curative care are quite concrete whereas awareness of this aspect is less pronounced in neurological symptoms. “The scientific evidence for interventions in neuropalliation is still limited,” explained Prof Marianne de Visser from the Academic Medical Centre of the University of Amsterdam and co-chair of the EAN Scientific Panel on Palliative Care. “It is therefore crucial that we can now draw on a joint Consensus Review issued by the European Association for Palliative Care and the European Academy of Neurology. This EAPC-EAN paper summarizes the essential recommendations on the basis of the available data.”

The results of this landmark publication sparked many discussions at the 3rd Congress of the EAN in Amsterdam. Along with a scientific session chaired by Prof Oliver and Prof de Visser, the special needs of neurological patients were also discussed at a symposium jointly organised by the EAN and EFNA, the umbrella organisation for the European patient advocacy groups in neurology.
There may not be a sure formula for optimum lifelong palliative care, but the experts have been able to work out fundamental approaches. Prof Oliver: “There is evidence that starting palliative treatment as early as possible and taking a multidisciplinary approach can improve not only symptoms but also psychological and family/carers issues. In some diseases with a relentlessly progressive course such as amyotrophic lateral sclerosis palliative care starts with breaking the bad news of diagnosis. This requires specific skills and if not done properly, it may have a devastating effect on patients and carers. Beyond that, other important factors are improved communication, the precise assessment and treatment of the symptoms and improved training in the principles and knowledge of palliative medicine.”

**Care as a crucial element for patients as well as family members and caregivers**

Along with increased care for the patients, support must also be provided to all caregivers involved. Prof de Visser: “Caring for palliative patients always means physical and emotional stress. Without appropriate support, it can also cause bouts of depression. In many cases, caregivers need psychological support to work through their grief after a patient dies.”

**Intensified collaboration between neurologists and practitioners of palliative medicine**

These findings are coming at the right time for neurologists, with a steadily aging population. Prof Oliver: “Across Europe, there is a growing interest and major advances in this area. In many cases adequate palliative medical care is not just a question of resources but also one of attitude. If this changes, small modifications crucial to the patients and their families can often be achieved.” Prof Marianne de Visser, a specialist in neuromuscular diseases, considers this joint work to be just the first step toward improving collaboration between neurologists and practitioners of palliative medicine: “We hope this Consensus Review will give impetus to further discussions about the role of palliative medicine in neurology.”

In each case, the experts from both fields want to continue this successful collaboration in the future. Prof Oliver: “The Consensus Review is just the beginning of an unfolding collaboration between palliative medicine and neurology.” The topic will also be delved into more deeply and updated next year at the EAN Congress in Lisbon in a symposium jointly staged by EAN and EAPC. Prof de Visser: “We want to emphasize this collaboration for the well-being of our patients.” Prof Oliver was also convinced of this fact so both sides can only profit: “Neurologists must expand their knowledge of palliative medicine. Conversely, the specialists in palliative medicine must gain greater expertise in neurology. That is why, on both sides, we must be consciously open to learning about the disciplines on the other side and collaborate together.”


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