

## RESEARCH NEEDS IN NEUROLOGY

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Palliative Care in Neurology is a growing field of interest to Neurologists worldwide. Similar to Oncology some years ago, it adds a new perspective and dimension to the care of patients with neurological diseases and their families.

As this is a new field, many even basic facts are unknown. Therefore, research needs are huge and might be divided into four aspects:

1. Identification of needs: Aside from the situation of patients with ALS, for patients with other neurological diseases such as brain tumors or muscular dystrophy, hardly anything is known about the prevalence of symptoms, the specific psychosocial needs, the cause and quality of death, and bereavement problems. The first studies looking into these questions are currently underway. It should be the aim of these studies to create a patient-generated ideal trajectory of care for each neurological disease.
2. Structure Analysis: If one wants to improve the palliative care of neurological patients, the structural aspects how neurologists are trained and educated, where and by whom neurological patients are seen, what organisational support is currently available, must be analysed. These aspects might differ enormously between countries, even within the European Union. These structures of the current trajectories must be analysed to compare them to the ideal trajectories identified above.
3. Methodological Research: Still a lot must be learned about our assessment measures and the aims of our research. What primary outcome measure do we want to achieve ("quality of life"?) and how valid are the instruments we use to measure them. Even in the secondary measures such as symptom control, hardly any scale used in oncological palliative care has been validated for the use in Neurology.
4. Intervention Studies: Once we have done our "homework" in points 1-3 above, the real questions can be started to be tackled. Based on hypotheses what should be changed, these measures taken must be controlled in intervention studies to the aim of improving the situation of the dying patients in Neurology.

The international Working Group on Palliative Care in Neurology, a research group of the World Federation of Neurology, is a worldwide group of neurologists, which is currently working on some of these aspects, such as writing a textbook, setting up a core curriculum and planning some structure analysis in several European countries.