

LETTER TO THE EDITOR **OPEN ACCESS**

Re: “Palliative Care in Europe: Safeguarding Compassion Amidst Changing End-of-Life Policies and Expanding Access to Medically Assisted Dying Position Statement on Behalf of the European Academy of Neurology, the European Federation of Neurological Associations and OneNeurology”

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Dear Editors,
We would like to thank Pucci et al. for their interest in our position statement, in which we strongly advocate for timely, unrestricted access to high-quality palliative care for people living with long-term neurological conditions (PwLTNC) across

Europe. In our statement, we emphasize that medically assisted dying (MAD) must never be introduced in response to deficiencies in care provision or as an alternative to comprehensive, multidisciplinary palliative care [1]. The joint development of this statement by the European Academy of Neurology (EAN)

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and two patient organizations (the European Federation of Neurological Associations, and OneNeurology) is particularly important, as this partnership ensured that patient perspectives were meaningfully and equitably represented, alongside those of clinicians [1].

Palliative care provides essential relief from suffering, supports patients and their families in an integrated manner, and helps preserve dignity and quality of life throughout the disease trajectory. Yet, it remains poorly integrated in the care for PwLTNC. In a recent survey, European Neurologists expressed their dissatisfaction with the availability of long-term healthcare, including palliative care, and in particular psychosocial and spiritual support offered to PwLTNC, their families and carers and the resources to provide healthcare for PwLTNC in medical emergencies [2]. Timely access to comprehensive, multidisciplinary palliative care across Europe remains a key unmet need.

We are grateful to the authors for providing the context of current Italian legislation. Nevertheless, it is important to emphasize that legal frameworks regulating MAD vary substantially across European countries. As a pan-European scientific society, the EAN does not seek to evaluate or validate national legal frameworks, but rather to emphasize the clinical, ethical, and patient-centered principles that should guide care for PwLTNC.

LTNC are well known to substantially impair quality of life for affected individuals and their families. PwLTNC may face profound threats to personhood and autonomy, often in the context of an uncertain prognosis [3, 4]. Indeed, LTNC are frequently represented among the underlying diagnoses in requests for medically assisted dying [3, 5]. Therefore, we fully agree with Pucci et al. that neurologists need to be appropriately equipped to lead such conversations with competence, sensitivity, and compassion, and to provide patients with balanced and comprehensive information about all available options, while holistically managing their physical, psychological, social, and spiritual needs. We thank Pucci et al. for contributing to this important discussion.

Author Contributions

Katarina Rukavina: conceptualization, writing – original draft, writing – review and editing. **Marianne de Visser:** writing – review and editing. **Elena Moro:** writing – review and editing. **Kailash Bhatia:** writing – review and editing. **Paul Boon:** writing – review and editing. **Jana Midelfart-Hoff:** writing – review and editing. **Matilde Leonardi:** writing – review and editing. **Irena Rektorova:** writing – review and editing. **Gereon R. Fink:** writing – review and editing. **Nathalie Nasr:** writing – review and editing. **Alicia Gonzalez-Martinez:** writing – review and editing. **Claudio L. A. Bassetti:** writing – review and editing. **Ulf Kallweit:** writing – review and editing. **Michael Crean:** writing – review and editing. **Patrick Cras:** writing – review and editing. **Ludo Vanopdenbosch:** writing – review and editing. **Astri Arnesen:** writing – review and editing. **Joke Jaarsma:** writing – review and editing. **Alexander Bernhard Kowski:** writing – review and editing. **Simone Veronese:** writing – review and editing. **David Oliver:** writing – review and editing, conceptualization.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

Linked Articles

This article is linked with Rukavina et al. To view this article, visit <https://doi.org/10.1111/ene.70591>.

References

1. K. Rukavina, M. de Visser, E. Moro, et al., “Palliative Care in Europe: Safeguarding Compassion Amidst Changing End-of-Life Policies and Expanding Access to Medically Assisted Dying Position Statement on Behalf of the European Academy of Neurology, the European Federation of Neurological Associations and OneNeurology,” *European Journal of Neurology* 33, no. 4 (2026): e70591, <https://doi.org/10.1111/ene.70591>.
2. K. Rukavina, A. Solari, M. de Visser, et al., “Healthcare for Adults With Long-Term Neurological Conditions: European Academy of Neurology Members Survey,” *BMJ Supportive & Palliative Care* 16, no. 3 (2026): 620–627.
3. C. L. Vaughan and C. Sucre, “Medical Aid in Dying: An Overview for Neurologists,” *Practical Neurology* 24, no. 2 (2025): 18–28.
4. T. E. Gofton, M. Chum, V. Schulz, B. T. Gofton, A. Sarpal, and C. Watling, “Challenges Facing Palliative Neurology Practice: A Qualitative Analysis,” *Journal of the Neurological Sciences* 385 (2018): 225–231.
5. L. Shavelson, T. M. Pope, M. P. Battin, A. Ouellette, and B. Kluger, “Neurologic Diseases and Medical Aid in Dying: Aid-in-Dying Laws Create an Underclass of Patients Based on Disability,” *American Journal of Bioethics* 23, no. 9 (2023): 5–15.