

Palliative care: Creating a new model to address suffering for neurological illnesses

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Neurologic illnesses, including Alzheimer's, brain cancer, amyotrophic lateral sclerosis (ALS) and stroke, are among the most dreaded illnesses in medicine and leading causes of disability and death worldwide.

Despite the huge burden of suffering these patients and families face, palliative care is not routinely offered and is used far less than in other illnesses.

In a review commissioned by *The Lancet Neurology* journal, an international team of experts argue that current models of care do not adequately address the needs of people living with neurologic illness. They propose a new evidence-based framework for early and ongoing [palliative care](#) approaches that can be employed by multiple members of the healthcare team to improve quality of life for individuals with neurological disorders and their families.

"Suffering is the fundamental concern of palliative care. To improve care we must address the total pain of neurologic illness—not just physical pain, but also psychological, social, and spiritual distress," said University of Rochester Medical Center neurologist Benzi Kluger, MD, lead author of the article produced by members of the International Neuropalliative Care Society. "This model of care seeks to screen for and prevent suffering by integrating an early approach to palliative care, with neurologists, and other clinicians who care for people with neurological illnesses incorporating a palliative care approach from day one."

Nearly all [neurological diseases](#) cause a wide range of symptoms, including pain, fatigue, and memory loss. Depression, anxiety, [social isolation](#), and loss of independence are also common. Family members typically are the primary at-home caregivers and over time can struggle with the [emotional impact](#) of seeing a loved one suffer as well as with the social, financial and physical impact of providing care.

Building on international palliative care guidelines and a review of neuropalliative care research to date, the authors propose a new model of care carried out by an extended health care team that anticipates the

changing needs that arise over the course of a neurologic illness. The model begins by recognizing that simply receiving a neurologic diagnosis is a life-changing event that merits emotional support and expert guidance.

From there, efforts are made to screen for invisible symptoms like depression, to help patients and families plan for the future, and to make full use of an extended healthcare team including social workers, mental health specialists, spiritual care, rehabilitation and pain medicine. Efforts must also be made to improve end-of-life care to allow patients to live with dignity, control, and comfort for as long as possible.

"There are long-term goals associated with policy changes that we highlight in this paper, but there are things that we can do right now that can go a long way to improving care," said Kluger. "Some of this can be achieved by empowering neurology teams to provide better whole person, patient-centered care. We can also work with insurance companies and hospitals to incentivize care that improves patient and family outcomes while reducing costs and unwanted hospital stays."

The authors cite numerous research studies from Parkinson's disease, multiple sclerosis, dementia and other neurologic illnesses demonstrating the promise of palliative care approaches to improve several key outcomes including quality of life, symptom management, future care planning. Notably, integration of palliative care for neurologic illness is increasingly recommended in guidelines from national and international foundations, and the Parkinson Foundation has launched an ambitious project funded by the Patient Centered Outcomes Research Institute to make integrated palliative care a new standard throughout its global Center of Excellence network.

"The focus needs to be on the immediate and practical work of helping to prevent and alleviate suffering," said Kluger. "If we use that as our

north star, everything else will follow suit. Almost everyone will be affected by neurologic illness at some point in their life—as either a patient or a family caregiver. I believe this is the ultimate test of our healthcare system. Are we going to finally provide the care and support people need? I'm hopeful that we can."

More information: Palliative care to support the needs of adults with neurological disease, *The Lancet Neurology* (2023). [DOI: 10.1016/S1474-4422\(23\)00129-1](https://doi.org/10.1016/S1474-4422(23)00129-1)

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