Neuropalliative Care as a Way of Being

Luciana Oliveira Neves, PhD, MD
Neurologist and Palliative Care Specialist
Hospital Unimed Fortaleza and Hospital Regional do Sertão
Central, Ceará, Brazil

I am a Latin American, Brazilian woman, wife, mother, neurologist, and palliative care physician. While Neurology has taught me about the nervous system, it is palliative care that has taught me to truly understand people — and myself.

In Neurology, we engage with people living with pain, progressive diseases, and cognitive, physical, social, and financial limitations daily. In this context, a palliative approach is not just complementary—it is essential. I realize I was drawn to palliative care even before I knew it had a name.

I left my homeland in the north of the country, in the Amazon Rainforest, traveling approximately 5,000 km to complete my undergraduate degree in Medicine (2003) and my specialization in Neurology (2009), carrying a persistent restlessness. I was not interested only in anatomy or pathophysiology, but also in patients' stories, suffering, and life contexts. I was often mistaken for a student of nursing, psychology, or social work, which made me question whether I was truly meant to be a physician. Today, I understand that this confusion was, in fact, a sign of coherence and of my strength.

In 2011, I enrolled in a postgraduate program in palliative care in Ceará, and it was palliative care that gave name, language, and foundation to long-standing concerns. From that moment on, it became impossible to dissociate neurology from palliative Care.

When working with my patients in palliative care, I faced many challenges. One of them is health insurance, because palliative care was not considered deserving of reimbursement. Choosing to work in palliative care while practicing neurology in other settings often resulted in professional invisibility, increased responsibilities, and insufficient structural support. I developed a project for an integrated stroke and palliative care pathway that, despite its clinical relevance, did not move forward because palliative care was not yet considered a strategic priority. I pursued my passion in palliative care despite the many challenges, as in Brazil, palliative care is still in the early stages of recognition and needs greater support for full integration into institutional priorities. I do not view these challenges as failures of people or institutions, but rather as reflections of the complex challenges that remain for health systems to incorporate palliative care into neurological practice fully. I learned that we need to continue changing with courage. We must see neurological patients as inherently integrated with palliative care, without distortions and without concessions that are misaligned with its purpose.

Over time, I have also witnessed the emergence of a collective movement: the transformation of the Palliative Care Center of the Brazilian Academy of Neurology into

a formal commission, along with invitations to give lectures, contribute to book chapters, and participate in position papers. There is still a long road ahead, but change is happening. I have changed.

Today, I understand that neuropalliative care is not merely a professional choice; it is about the kind of human being we want to be. I am one whole human caring for another who wishes to remain whole. We are far more than neurons, arteries, and diagnostic hypotheses. Neuropalliative care is a living, global movement, and a science that deserves study, recognition, and genuine commitment. For me, it is a way of being.