

# MONTHLY Feature

## Palliative Care in Neuromuscular Disease: Thinking Beyond Death and Dying

When people think of palliative care, they often think of death and dying. While hospice care, which is part of palliative care, is reserved for terminally ill patients during the last six months of life, palliative care can be utilized throughout the course of disease and treatment of a life-limiting condition. For individuals living with neuromuscular diseases, which are often life limiting, palliative care can be life changing.

Unfortunately, stigma and lack of knowledge prevent palliative care from being touted as essential to quality of life for many people with neuromuscular diseases. We talked to Vanessa Battista, MS, RN, CPNP-PC, a nurse practitioner with the Neuromuscular Program at Children's Hospital of Philadelphia (CHOP), and Sarah Stoney, MSW, LSW, a social worker in the Pediatric Multiple Sclerosis Clinic, Neuromuscular Program, and Leukodystrophy Center at CHOP, about their experiences providing palliative care and thoughts on how to address stigma to help the field evolve.

### Understanding Palliative Care

When it comes to palliative care, there is a big difference not only between hospice care and palliative care, but also between adult and pediatric palliative care. Many neuromuscular diseases affect babies and children, so this is an important distinction to make, Battista says.

One major point of difference with hospice care is in the World Health Organization's (WHO) definition of palliative care. "It includes the family in the definition," Battista says, "and it mandates that care be provided for the mind, body, and spirit, and where that family is at that time — so it encompasses all the pieces."



Vanessa Battista, MS, RN, CPNP-PC



Sarah Stoney, MSW, LSW

Palliative care can start immediately after a diagnosis is made and should include care and support surrounding not only pain and symptom management, but also decision-making to establish goals of care throughout the disease course.

### Palliative Care in Action

From a pediatric perspective, palliative care can start at the time of diagnosis for many families, Stoney says, although it is usually introduced on a case-by-case basis and only if the family and provider agree to this plan for additional care. If the disease is predicted to be life-limiting and there will be decisions to make regarding quality of life on an ongoing basis, she says, "those are all families for whom we believe that palliative care could be beneficial." At CHOP, they can introduce the option of palliative care to families as early as the time of diagnosis instead of waiting for an urgent situation to arise, allowing the family to establish a relationship with their team. "In these situations, families can benefit from an added layer of support from a team they have gotten to know," Stoney says.

Recently, standard care has changed because new treatments are available. According to Battista, this tempts some families and providers to say they don't need palliative care. "However, I think the piece that is now more important than ever is the decision-making process [around what treatment options families want to pursue]," she says. Several interdisciplinary team members, including genetic counselors, will address options with families in diseases where treatments currently exist, such as spinal muscular atrophy (SMA). However, palliative care can be immensely helpful for both providers and family

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members when weighing these options. “For most diseases with treatment, yes, absolutely go ahead with treatment, but there are still decisions to make,” Battista says. “We still need to talk with families about their goals and what is best for them as an individual or for their child and family.”

Stoney believes that palliative care is best given with the mindset that while therapies exist, parents still need the emotional support that palliative care offers. “These parents are still caring for extremely sick children — these are very serious diseases, none of the treatments are curative, and we still need to be supporting families in the same way that we did before.”

## Reducing the Stigma of Palliative Care

Both Battista and Stoney believe the field must address the stigma associated with palliative care — that it is all about death and dying — which is one of the biggest challenges to employing it widely and effectively. “Many patients are thinking about dying, so to not provide them a supportive place to talk about it is robbing them of a critical piece of their disease management and care,” Stoney says.

Supporting individuals with neuromuscular diseases and their families includes having “conversations about death,” Battista says. Providers shouldn’t be afraid to bring up the fact that many neuromuscular diseases are, in fact, life-limiting. Encouraging patients to talk about what they want their future to look like will go a long way toward holistic healing. She adds that palliative care is moving increasingly into specialty areas, such as neuromuscular disease. “We’re now moving more toward training subspecialty providers in hospitals to do primary palliative care, that is, teaching skills to healthcare team members to have conversations about these topics with families.”

Both Battista and Stoney say that education and awareness are key to moving palliative care out of the shadows. Educational sessions at conferences — for affected individuals and families, as well as providers — will continue to improve upon the stigma and lack of understanding. Battista would like to develop a “modular training for neuromuscular providers where we could tailor palliative care specifically for

## DEFINING PALLIATIVE CARE FOR CHILDREN

Palliative care for children represents a special, albeit closely related field to adult palliative care. The World Health Organization’s (WHO) definition of palliative care appropriate for children and their families is as follows:

- Palliative care for children is the active total care of the child’s body, mind, and spirit, and involves giving support to the family.
- It begins when illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child’s physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources. It can be implemented successfully even if resources are limited.
- It can be provided in tertiary care facilities, in community health centers, and even in children’s homes.

These principles apply to other pediatric chronic disorders.

neuromuscular diseases and give providers tools to have in their toolbox.”

Adds Stoney: “I think any education that large support organizations such as MDA can do to empower providers to have more of these discussions with patients, and to make them feel more comfortable having these challenging conversations, will make a world of difference.”