

PALLIATIVE CARE

CAN BE A VITAL SUPPORT

IN ALS AND OTHER

NEUROMUSCULAR DISEASES

Palliative care is specialized medical care aimed at increasing comfort, improving quality of life, and providing support to patients and families facing a serious illness. It can be appropriate at any stage of a serious illness and, in contrast to hospice care, isn't exclusively for people who are in their final months of life.

While hospice is a service for people with a prognosis of less than six months to live, palliative care can be appropriate from the time of diagnosis and may be used along with treatment intended to cure illness and prolong life.

Kara Bischoff, MD, medical director of the Outpatient Palliative Care Service at the University of California, San Francisco, explains that palliative care takes a patient- and family-centered approach. "Palliative care is team-based care — typically involving a doctor, nurse, social worker, and spiritual care provider — to support a person facing a serious illness and their family," she says.

Dr. Bischoff categorizes services provided through palliative care in three buckets:

1. Symptom management, which includes addressing physical symptoms (e.g., pain, shortness of breath, nausea, or insomnia) and emotional symptoms (e.g., depression, anxiety, or difficulty adjusting to living with a serious illness)
2. Care planning, which involves helping patients and their families get information and supporting them in making decisions about their care
3. Supporting patients and their families along the illness journey

Palliative care for ALS

"In recent years we've seen many patients with neuromuscular diseases such as ALS [amyotrophic lateral sclerosis]," Dr. Bischoff says. "People with ALS often have needs that fall into all three of the buckets I mentioned. They have many symptoms, they face important decisions about their care — including whether they want interventions such as a feeding tube or a breathing machine — and I find family caregivers of people with ALS have many needs because the caregiving role is so intense."

For patients with ALS, palliative care can address symptoms that cause discomfort, such as muscle cramps or excessive saliva, and work with patients and their caregivers on strategies to help the patient communicate, eat, or breathe more comfortably. Palliative care also can help patients and families learn and make decisions about more involved treatment options, such as mechanical ventilation via tracheostomy.

Caring for caregivers

Palliative care can do as much for family and other caregivers as for patients.

"Everyone in a family is affected by a serious illness, but in different ways," Dr. Bischoff says. "We often ask caregivers how they're doing and address their questions and concerns because we care a lot about them, too." This kind of support ultimately is good for the patient as well as the caregiver, because caregiver well-being affects a patient's care and outcomes, and patients often worry about their caregivers.

Palliative doesn't necessarily end with the patient's death. "Palliative care is there to give support both before and after a patient passes away," Dr. Bischoff says. Her team frequently reaches out to family members after the death of a patient to offer support and connect them with ongoing bereavement support. "We want families to know that we're always here for them, even long after the death of a loved one; we don't forget them," she says.

Starting palliative care

There isn't a wrong time to start palliative care.

"Whenever someone has a serious illness and they need more attention to their symptoms, help making decisions about their care, or support to navigate the illness than their ALS care team can provide, that's an appropriate time for a referral to palliative care," Dr. Bischoff says. For some people, palliative care can be appropriate from the time of diagnosis, while for others it will be later in their journey.

Generally, the patient needs a referral from their physician to get insurance coverage for palliative care services. Dr. Bischoff believes it is important for patients and their families to feel empowered to request a referral from their ALS care team or primary care physician.

"Palliative care is just one aspect of a comprehensive medical team," she says. "It's there for guidance, comfort, and to be an extra layer of support."