

## Post-Polio Thoughts

Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska, ([n.carter@cox.net](mailto:n.carter@cox.net))

### A BETTER LIFE

It's time we got this straight: palliative care is not the same as hospice.

As Karen Rafinski put it in June's AARP Bulletin, "Palliative care is about making the most of life with a serious illness, whether the disease is terminal or not." While this could mean patients with life-limiting illnesses, it means those who may be recovering from grave conditions such as cancer or stroke, as well.

And guess what: It can also be us—certain polio survivors, perhaps still living at home but not necessarily bedridden, who simply want a better life. They may be severely affected by pain, for instance, or chronic weakness or stress—survivors using ventilators or those losing more muscle mass—others additionally affected by complications of aging. A better life. We're talking quality here (not to mention quantity—at least one study shows patients living longer for having been involved in palliative care).

Todd Sauer, MD, Medical Director at Nebraska Medical Center's three-year-old Palliative Medical Service in Omaha, says, "We are experts at helping to manage symptoms. We bring comfort to patients far earlier than they would find by merely seeking end-of-life care. We also offer help in making decisions. We meet with families and patients to discuss options, to open their lives to a variety of possibilities."

Traditionally, palliative care programs use a team approach. Teams are often made up of a physician (probably different from our primary care doctor, though the palliative doctor does work with others to coordinate care), nurse practitioners, social workers, and chaplains, as well as patients and, at times, family members. Such teams cover a wide range of symptoms by addressing physical, emotional, and spiritual issues.

A holistic approach to one of our major concerns, pain management, may be used. In addition to medication, it's possible to try massage therapy, acupuncture, or any of an assortment of relaxation techniques, such as yoga and other meditation methods. Much attention is paid to the type of pain involved. Emotional pain is far different from a nagging rotator cuff, yet both kinds of pain must be tended to. Many patients undergoing standard treatment for their specific disease discover that palliative programs add an amazingly helpful layer of support.

In Omaha, members of the palliative care team make home visits at any stage of a patient's illness. "While a doctor can't be available to visit people in their homes 24/7," says Dr. Sauer, "we do the best we can. We also make every effort to help families caring for their loved ones at home." Check with your doctor about what Medicare covers.

Not all palliative care programs are alike—and neither are all patients. We need a good fit. Shop around—[check out the list](#) of what's available in your locality at [getpalliativecare.org](http://getpalliativecare.org) (see Step 2) or ask your doctor for a referral.

What to look for? As an example, Dr. Sauer is board certified in Family Medicine with a subspecialty in Hospice and Palliative Medicine. He's Fellowship trained, comes into the picture with outstanding credentials. Here's a family physician who liked treating families enough to move on to devote time and effort to becoming skilled in the world of palliative care. Those all have to be clues.

Today you and I may believe we don't have a reason for palliative care—could be we're not sure, or we're thinking maybe later it would be a good idea. How could it hurt to get in touch with a palliative care doctor and discuss options?

O.K. Have you looked it up yet? The word "palliative"? Alleviation of symptoms. To mitigate. To reduce the severity.

Sweet, sweet sounds to my ears. What do you think...

*Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.*

Source: Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org))