



Benton  
Hospice  
Service

## **CHANGE IN THE NATURE OF TERMINAL ILLNESS**

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The nature of the illnesses that bring people to Benton Hospice Service is changing.

While the number of our cancer patients has remained relatively stable, we are caring for an ever-growing number of people with non-cancer diagnoses. These include Alzheimer's and other dementias; heart, lung, liver, and kidney diseases; and "failure to thrive," a new way to explain the age-old problem of a body wearing out. One local physician calls it "the dwindles."

This gradual change in the types of illnesses our patients are experiencing requires our care team to make adjustments.

Caroline Zaworski, BHS nurse for fourteen years, notes how different the trajectories of decline are for cancer and non-cancer patients. Cancer usually takes a foreseeable downward path. Illnesses like heart, lung, or kidney disease have many ups and downs, making their final stages difficult to predict. Non-cancer diseases tend to be chronic in nature, and families often have been dealing with the diagnosis for a long time. Nurses have to be alert to changes in the patient's condition that may be very subtle. "I find that I spend much more time with families of patients with heart, lung, or kidney diseases trying to help them understand the various possibilities of what to expect and how to prepare," Caroline says.

One non-cancer diagnosis that presents unique challenges is the various forms of dementia. Nurses use advanced assessment skills to understand what is going on physically when the patient isn't able to verbalize. Nurses provide guidance to families on difficult issues, such as how to respond if the patient doesn't want food anymore. Behavior changes in particular can be distressing to families, who remember their loved one differently and grieve for that "lost" person. Developing a comforting relationship with the patient with dementia is also a challenge for hospice team members.

Caregiver fatigue is more often apparent in chronic or long term disease cases. Supporting exhausted family members becomes a bigger area of concern for the social services team. Respite Care Volunteers, who provide breaks for caregivers, require more diverse training on how to care for those with dementias or general debility as they are more frequently asked to help out in those situations.

Marsha Gulick, BHS Spiritual Care Counselor, notes that people with cancer are often mentally alert until they die. She provides spiritual care for someone with dementia in different ways. Providing a presence is often the best way to reach someone spiritually. "As a person's cognitive ability declines, sensory experience becomes more

important,” explains Marsha. “Singing, looking at pictures, talking about past experiences or interests, or holding a hand are good ways of connecting with dementia patients.”

As patient needs change, everyone on the care team adapts. Our nurses adjust their approach to managing pain and providing symptom relief for those who are in the end-stage of chronic disease. We have more home health aides on staff to assist with personal care and more social workers and nurses with specialized training for dealing with patients with dementia. Whatever the diagnosis, Benton Hospice Service remains dedicated to providing compassionate, professional care at the end of life.

