



Benton
Hospice
Service

ENCOURAGING PATIENT CONTROL

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by Marie Oliver

“Dying is all about losing control,” says Doug Hare, staff nurse at Benton Hospice. “You lose it in increments. Each loss is a little death.” For hospice workers, the challenge is to help the dying feel that they still have some control—to help them spend their last days in as much emotional and physical comfort as possible.

It’s not as easy task. Sometimes it means accepting a patient decision that would not be the choice of the hospice worker or the caregivers.

Fiona Standen, licensed clinical social worker, tells the story of an “old biker” who chose to spend his last days in a townhouse filled to overflowing with clutter. As the days went by, more junk appeared, until the bed became inaccessible to caregivers.

“In his final days, it became almost impossible to care for him,” says Fiona. The patient’s caregivers were upset and wanted him to go to a nursing home. Fiona managed to calm everyone down and helped to clear a space around the bed. The patient died peacefully within 48 hours. “After he died, his partner thanked me for allowing him to die at home,” says Fiona.

Sometimes patients won’t accept drugs for pain management, or they decide to stop eating. When patients are admitted to hospitals or nursing homes, staff may discourage much patient control as they include the patient in the facility’s routine. Hospice takes a different approach, offering patients informed choices in small as well as critical decisions.

Often a patient will change his or her mind about using pain management after exercising the choice not to use it. Many times the decision comes from a fear of needles, so hospice workers offer alternative delivery methods that are more comfortable for the patient.

“Pain is a great motivator,” says Doug. But the patient’s decision is final.

A patient’s refusal to eat can be a measure of control over his or her death, explains Fiona, so her work becomes a process of helping caregivers to understand and accept the patient’s choice. “My work is never to change the patient’s mind,” she says.

Sometimes the need for control comes out in odd ways. Jackie Stankey, patient care coordinator, tells the story of the time she received a frantic phone call from the wife of a dying man. The man wanted three ice cubes in his water, but the wife wanted to give him only two. “This ‘nothing’ issue had become really important,” says Jackie.

In a case like this, the hospice worker tries to help both patient and caregiver see that the “nothing issue” is driven by an underlying real issue. The wife, as primary caregiver, was being “run ragged” by the patient, says Jackie, and really needed a break. The patient needed to allow it and the caregiver needed to accept it for herself.

“As someone gets more ill, they don’t have the energy to deal with others, or have a recognition of what others might need,” she says. It’s up to the hospice worker to make sure everyone’s needs get met while still allowing the patient a sense of being in control of the situation.

Jackie says children of the elderly often unwittingly compromise their parent’s ability to exercise control of their dying process. These adult children, other family members, or even some health care professionals may attempt to make decisions the elderly person is quite capable of making for him/herself. In such situations, the hospice team’s role is to advocate for the patient and gently help the well-meaning family respect their dying loved one’s wishes.

Caroline Zaworski, staff nurse, says that sometimes patients, particularly the elderly, may need permission to be in control. Realizing they can have some say over how their last days will be is both liberating and refreshing for them. They’re surprised that, with pain management and special equipment, they can often still do things they like to do for a time, such as go to the beach or out to dinner.

Emotional needs are as important to consider as physical needs, Fiona says. She tells the story of a man whose dying was complicated by “hidden secrets.” He felt he needed to make amends to certain people before he died, so Fiona facilitated that process.

Ultimately, death comes to each of us in its own time and in its own way. Until then, allowing the dying to maintain a measure of control over their lives is an honoring of their spirit. Each day, hospice workers are challenged to respect a patient’s last wishes, even when it’s professionally difficult. As Doug says, “We go into the homes to serve.”