

THE TRIPLE C

Caring, Compassion & CHOICE



“We affirm life”: Caring for Dementia, Alzheimer’s Patients from a Hospice Nurse’s Perspective

Source: Anna Claire Vollers

“When you lose somebody with dementia, it’s almost like you’ve lost them twice.”

Marsha Farrell is intimately familiar with the toll that a dementia or Alzheimer’s diagnosis takes on the family members of the person with the disease. She’s a registered nurse, a certified hospice and palliative nurse, and the education coordinator for Hospice Family Care in Huntsville, Alabama.

Farrell has worked with many families struggling to care for loved ones with dementia or Alzheimer’s. “It’s a long process of anticipatory grief,” said Farrell. “Every little thing they lose, you grieve – when your mom can’t walk anymore, then when she can’t use a wheelchair anymore, then when she can’t remember who you are. The patient grieves when they can’t remember how to get home, then can’t remember how to carry on a conversation. There are all these losses that families are dealing with constantly throughout the disease.”

Caring for a loved one with dementia or Alzheimer’s can be an exhausting process, both physically and emotionally. It can also be a long process, since a person could live 10 or more years past the original diagnosis thanks to early detection. Farrell stresses the importance of family caregivers taking good care of themselves. “We don’t need to burn out caregivers and ruin their health,” she said. “Always, always ask for help.”

Support groups in the community are available for these caregivers. The Alzheimer’s Association offers tips for caregivers on how best to manage their own health while looking after someone else’s. The AA website also offers information about topics like caregiver stress, depression, relationship changes and grief/loss.

Farrell also points out that part of asking for help is being honest with doctors, and being willing to ask the hard questions about the parent or spouse’s realistic prognosis. Is he or she in the late stages of the disease, and might be appropriate for hospice care?

“Sometimes the doctor may not want to bring it up,” said Farrell. “I encourage caregivers to bring it up so they can understand where they are.” Many people are uncomfortable with the idea of asking about hospice, said Farrell, associating it with death or believing hospice is only brought in for the last few days of a person’s life.

“Hospice is not for people who are actively dying; it’s for people living with a terminal illness,” said Farrell. “If hospice is used appropriately, we would have people for weeks and months, rather than for days. “I like to say that all of my patients are 100 percent alive. We don’t take care of dead people – that’s for the funeral homes.”

A physician makes the determination if a patient is a candidate for hospice services. The Medicare guideline says hospice is appropriate for people who have been given an expected prognosis of six months or less. Medicare or private insurance pays for hospice services, which are administered by a team of registered nurses, home health aides, social workers, chaplains and volunteers.

Hospice assists the patient with medical care for pain and symptom management, processing paperwork and finding resources for financial support, and also providing support for family and caregivers. Grief and bereavement services are offered to family members for up to 13 months after the death of the loved one – to get them through the first anniversary of the person’s death.

“People shy away from the word ‘hospice’ and they don’t realize,” said Farrell, “that what we really do is we affirm life.”

Family Quote

“Thank you for sending your angels to care for my mother during her final days. It helped ease our sorrow knowing she was being cared for with such kindness, dignity and respect.”

Quote of the Month

“A word of encouragement during a failure is worth more than an hour of praise after success.”

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