

Having dedicated and informed volunteers visit residents with end-stage dementia is highly desirable. As non-medical personnel, volunteers have unique gifts to offer. However, in order to be more comfortable and accomplished in this difficult undertaking, they need specific, end-stage dementia-care education.

By Irene Barnes

Preparing volunteers for end-stage dementia care

While the atmosphere surrounding end-of-life dementia care continues to be highly charged, several innovative palliative care initiatives have been created. A number of studies have been carried out that examine the issues relating to effective palliative dementia care; i.e., the extended role of the volunteer, nutrition issues, ethics, the size of the palliative care team, for example, from a nurse case manager working alone, to a full-scope team consisting of a physician, OT, clinical nurse, etc. (Rabow, et al., 2004; Weissman, 2004; Baird et al., 2003; Henderson et al., 2003; Hurley et al., 2000 - 2002; Lamberg, 2002; Zerzan et al., 1999; Lynn, 2001; Kovach, 1998).

A unique role

Dementia is an illness that may last from a few years to many years until final closure is effected. More often than not, the person with dementia has moved through the care system, from a family home, to a retirement home or assisted living arrangement, to a nursing home. It is during these “up-rootings” that possessions become mislaid, and family

members, with their career or work commitments, become exhausted. This is also the time when friends vanish.

Many residents with end-stage dementia, who never had children, or whose family is spread throughout the world, are often without visitors. It is a critical time as the resident’s physical and supportive needs increase dramatically. Anxiety, fear and a sense of abandonment create a situation where the resident needs more attention than ever - which many nursing homes are unable to provide because of fiscal restraints and staff shortages.

Yet, many people have been comforted knowing that someone was with their loved one at the end. This “someone” is, more often than not, a volunteer.

Over the past few years, the desirability of having well-informed volunteers visit dementia care units has been recognized.

Specialized instruction

To enable palliative care volunteers to feel comfortable and useful to residents in late-stage dementia, and not

be intimidated by the challenges involved, a 100-bed nursing home in B.C. made the decision to provide dementia-care specific education to its volunteers.

The material on the following pages is part of a teaching plan (which eventually became a handout) developed specifically for volunteers visiting residents with end-stage dementia. Note that one of the key issues addressed is “communicating with the unresponsive resident with dementia.”

“Reduce or moderate”

Palliation refers to “reducing or moderating the intensity of an event or circumstance,” in this case, the circumstance of approaching death.

For volunteers, the experience of end-of-life palliative care for a resident with dementia is an education unto itself, albeit, challenging, at times stressful, but fundamentally rewarding and dignifying.

Palliative care in end-stage dementia is also more demanding than other types of palliative care. Preparation specific to the role, will make the care more manageable, meaningful,