

PROVIDING QUALITY OF LIFE AT END OF LIFE

By K. Ritchie

It may have seemed as though the world attended the passing of Terry Schiavo, the woman at the centre of a heated controversy concerning quality of life and death.

For most of us, the passing of a family member will be a much more personal event. However we, too, may be required to make decisions that can impact the quality of life and death for someone else. In the absence of a personal directive or an individual's continued capacity to make and express a choice, those decisions can be wrenching and can potentially create family rifts that last for years.

This is particularly true for the families of people with dementia.

Alzheimer Disease is a progressive, degenerative brain disease that increasingly diminishes an individual's capacity to function without help. In the late stages of the disease, people lose the ability to formulate thoughts and use language to express their wishes. Eventually, even motor skills like chewing and the simple act of breathing can be compromised.

In order to help families prepare for the decisions that lay ahead, the Alzheimer Society of Calgary created a unique workshop a subject that many people do want to talk about: "Quality of Life at End of Life".

Value the Individual

It is important to share the dying person's life story with other caregivers, particularly as may relate to fears and preferences: lights on, music off, many visitors, no visitors, blankets tight or loose. Spirituality and religious beliefs are also a vital part of the life story that families need to share. Always remember that a person's spirit remains until their death, so it is important to visit the person and find ways to communicate through touch, sound, and other senses, to bring comfort and meet their need feel to loved.

Make the decision they would

Make care decisions based on the values and beliefs of the person who is dying, rather than your own. "Extraordinary Care" attempts to prolong life using all available treatments, such as CPR, tube feeding, kidney dialysis, etc. "Conservative Care" maintains current health, such as providing insulin for diabetes. "Comfort Care" or "Palliative Care" aims to give comfort and relieve pain rather than treat illness or prolong life. Know that you may change the level of care given as health deteriorates.

Do not expect reprieve

Understand that the person is dying. The end-of-life stage for a person with dementia often begins when the person stops eating and starts to lose weight, about 2-6 months before death. Families should know that providing food and water through a feeding tube

or IV does not necessarily prolong life or ease suffering. As body systems shut down, a person may not be physically able to handle having fluids delivered in this way.

Take care of yourself

Often, family members are so focused on providing care for a person that they don't take time to care for their own physical and mental health. When family members can find ways to stay healthy and socially engaged, and see hope in their own lives, they can provide better care for someone else and will be better able to adjust to the loss after the person has died.

Grieve without a timetable

Since Alzheimer Disease is progressive and continuous, the grief experienced by families can also be progressive and continuous, until families may feel deplete of such emotion. However, the death of a person is still a significant loss, and signals a major lifestyle change. Feelings of grief may still occur; perhaps sooner *and* later.

As the camera lights illuminated so harshly in the situation of Terry Schiavo, one of the best things we can do for each other is write down our wishes for end of life care, and share it with all our family members while we can.

To find out more about the *Quality of Life at End of Life* workshop and other family care support services offered by the Alzheimer Society of Calgary, visit www.AlzheimerCalgary.com.

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