

Palliative care and a dignified death

By Carol Edwards, RN, GCM



Palliative care, by definition, is any form of medical care or treatment that concentrates on reducing the severity of the disease symptoms, rather than striving to halt, delay or reverse progression of the disease itself or to provide a cure. The goal is to prevent and relieve suffering and to improve quality of life for people facing serious complex illnesses.

As a geriatric care manager, much of my work involves palliative care. It's always a privilege to be with families during these challenging times. Regardless of the circumstances, even when care is palliative it never inhibits us from assisting our clients to maximize their lives to the fullest. Respecting personal values and choices while participating in advocacy for a client's wishes at home, in hospital or in long-term care is my mission, even when the conditions are adverse.

Maintaining quality of life

In Dr. Kübler-Ross's famous book *On Death and Dying*, she tells us about the five stages of dying and discusses the journey to the conclusion, which culminates in peaceful acceptance by both patient and family. Once this acceptance is reached, the goals of palliative care are relief from suffering, treatment of pain and other distressing symptoms, psychological and spiritual care, and providing support systems to help the individual live as actively as possible. Support is also given to sustain and assist the individual's family.

Understanding priorities

The teams that I work with recognize that personal expectations and beliefs become increasingly important as life draws to a close. Last commitments and decisions are often the culmination of a person's life and must be respected. A good death is not to be underestimated and feeling a sense of achievement and satisfaction,

with no regrets, as life draws to a close surely must rank high. We also recognize that the family's time together is precious. Facilitating memory sharing and giving clients the opportunity to be surrounded by their loved ones are essential parts of care.

The best place

Palliative support and care can be organized and conducted in a variety of places, such as a hospital, palliative care centre, hospice or at home. The palliative care team can visit and manage care at home through government homecare, a private care provider or a combination of these. Family members are more often than not part of the team.

It is important that people are allowed to die on their own terms in the location of their choice, with the dignity that they deserve. There are some who want to spend their last hours in a facility where hospice and palliative care units offer the skilled care required.

However, many palliative patients still find themselves in a hospital when they would have

“The most important work you or I will ever do will be within the walls of our own home.”

Harold B. Lee

5 top risks to the elderly

1. Falls
2. Swallowing and feeding issues
3. Aspiration pneumonia
4. Gastric feeding tube versus a nasogastric tube
5. Resistive behaviours

preferred to end their days at home. Today, it is essential to know that there are excellent palliative teams who can provide care in the comfort of the family residence when necessary. In my experience, the clients who have been well cared for at home have had the most peaceful deaths that I have witnessed.

Something can be done

Unfortunately, palliative care is an area of specialization that is often under-taught during nursing and medical training, underestimated as a priority and, in many parts of the country, underfunded. Palliative care at home often becomes a reality as a result of family advocacy or careful pre-planning. Don't hesitate to ask for a palliative care team or insist on specialist support to meet a loved one's needs.

Nurses primarily manage a palliative client's care with skilled medication management from attending physicians. The nurses involved must be experienced, able to think on their feet, possess excellent assessment skills and have access to the state-of-the-art medical interventions necessary to provide excellent

nursing care during this critical time. A nurse may provide sedation or manage symptoms related to shortness of breath or other life-threatening symptoms.

Palliative care is often needed for a very short period of time, but in many cases it can be required for weeks or months. Some chronically ill patients manage to "hang on" until after a special event such as a family wedding or the birth of a grandchild. I have also seen clients who were declared palliative defy the odds and continue to lead productive lives at home and work for an extended period of time.

Obviously, when a person lives on for a longer period of time than expected it's most rewarding for all concerned, but it also can be difficult, especially if the individual appears to be suffering. Regular updates to the care plan based on the client's stability or changing needs as well as frequent discussions with the family are needed more than ever in these situations. These circumstances are quite emotionally charged for family members and friends and they may need additional support.

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Holding a Power of Attorney

A good power of attorney holder is someone who:

- strongly advocates for the person they are responsible for
- fully understands and accepts that person's philosophies of life
- is mature and responsible, honest, ethical and compassionate
- seeks professional and objective advice from professionals.

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“The miracle is this—the more we share, the more we have.”

Leonard Nimoy

Difficult decisions

It is important that any bad news is delivered by the physician in a way and at a pace that's appropriate for each individual. Sharing sensitive information with patients and their families must be personalized and may be better done in the presence of a social worker, a care manager or other impartial party such as a religious person.

The multiplicity and complexity of choices and their outcomes must be well described in an unbiased and non-judgmental way in order for everyone to understand the situation and make good decisions. At times like these families can become quite dysfunctional, given the immense stress and the opportunity for different opinions. My experience in these situations is that even well-educated, experienced people require an “interpreter” to discuss the information, acknowledge the implications and progress to the next stage of planning.

When you need to take charge

You will need a power of attorney (POA) in order to act on behalf of someone else. This is a legal tool for the protection of and advocacy for those who are unable to answer for their own wishes and well-being. It can be drawn up at any time during life, but its urgency increases in the presence of aging or disease. This document can be self-prepared or drawn up by a lawyer and is intended for the transfer of responsibility to a designated decision-maker.

The POA has two essential parts: personal care and property. Both are necessary when palliative care is needed. In essence, the person who holds the POA can become a substitute decision-maker for the person who is ill or dying.

The person who holds the POA for personal care may be asked to make decisions about health, treatment, housing arrangements, eating habits, safety, clothing and hygiene. He or she may also be involved in end-of-life decisions. The POA for personal care ceases at death. The person who holds the POA for property may have to deal with finances, assets and activities around budgeting, bill paying, financial management and care of property.

The responsibility of agreeing to be a POA can be onerous, and the obligation to the incapacitated person is that “decisions are made in a way that the person would have

done for himself or herself.”

Under most circumstances, a member of the family holds the POA. However, this may vary in the event of a dispute, when the court may assign decision-making responsibility to a third party.

Other “need to know” documents

You might hear about levels of intervention or do not resuscitate (DNR) orders. These documents allow families, under the guidance of health professionals, to select the level of care at various stages in a person's life. These may range from urgent and aggressive treatment to comfort measures only. Typically, people use a DNR order to detail the conditions under which they wish to be removed from a respirator or preferences associated with the use of life-saving equipment.

A living will or spoken desire is common. This is another preparation for incapacity, which people use to make a decision while they are still competent and able to decide their end of life interventions. A living will describes what life supports a patient wants or does not want. A living will needs to be taken into account by the family, the holder of the POA for personal care and the healthcare team.

End of life dignity

As I stress to the families I work with, there is always something that can be done to increase comfort and support. Most of us fear indignities as we deteriorate. When faced with this situation, however, it is surprising how we are able to adjust.

Surrounding loved ones with comfort and compassionate, thoughtful care is both a responsibility and a gift. There is a lot that families can do to make a difference. Ask professionals to share what they know and help you make the right decisions. Be part of education sessions where you can learn what to expect as situations change. And most of all, try to find ways to celebrate the times you and your loved one have shared. After all—a “good death” provides peace of mind for all concerned. ●



Carol Edwards, RN, GCM, is President of Careable, Inc. She can be reached at carol@careable.com or www.careable.com.