



# Compassionately managing care

By Andrea Nathanson, RN

**P**alliative and “care” are two words that may provoke fear and confusion in patients, their family members and loved ones. Palliative care means the compassionate care of a dying person by minimizing their suffering as they progress towards the end of life. Medically, this is achieved by helping dull the patient’s pain through assorted pain- and symptom-management techniques. However, more than just physical comfort measures can ensure that the remaining days (or years) of a patient’s life are comfortable.

Here is some helpful information I share with clients in my work as a registered nurse and primary palliative case manager. It may help you deal with a palliative care client and his or her family and inform you on how to best bring closure to someone’s life in a peaceful and positive manner.

## The stages of palliative care

Palliative care doesn’t just start when a patient is bed-ridden and near the end of life. Patients can receive treatment for various ailments and be ambulatory and independent when they first decide to seek palliative treatment.

Over time, a slow progression of pain or excessive weakness begins to set in and appetite will decrease. This usually signals the next stage of care: where the patient is unable to get around as easily as before. This typically indicates that a home-rest-bed scenario is imminent. From this point on, patients can experience issues and symptoms that result from immobility such as skin breakdown, muscle atrophy and increased weakness.

Once they are set up in bed, patients often stabilize or plateau before another significant decline in health occurs.

They usually “nest” in bed and become more comfortable with their environment. This is the stage where, hopefully, the family is talking with their loved one and emotionally connecting with them. It’s a time for comfort and visitors so that everyone can reflect upon their lives together.

## The discussion

The sooner a family can talk about the palliative situation, the better. Avoidance can lead to undue stress, resentment and even unbearable guilt over not having cleared the air. Professionals should encourage family members to communicate with the patient and with each other. Families also need to know that there are times when they’ll need to take a step back from the situation.

As a registered nurse, I usually begin dialogue with the patient long before any of the family does. Patients feel a sense of comfort when opening up a conversation about their emotional state, and together we strategize how and when they want to bring up the topic with family. I believe





my patient tends to confide in me because I stay objective and am not in denial about their condition. Family members appreciate and understand the uniqueness of this relationship that develops, and over time they too realize the value of this support for their own thoughts, fears and grief.

### **The benefits of home**

Caring for a loved one at home provides many advantages to the patient: frequent contact with loved ones, continuity of care, and the comfort of being in their own environment. I care for the majority of my palliative clients in their homes. While this scenario is often soothing for the patient, it is an adjustment for family members.

Families in a home palliative situation may fear that their loved one may be better off by being hospitalized. They feel the hospital may be a safer, more supportive place; however, this usually isn't the case. For the most part, palliative patients receive more consistent care at home and are more easily supported by their relatives and friends in a comfortable setting.

### **A range of emotions**

Professionals should expect a full range of emotions to emerge from the family members of a dying loved one.

Families should react to a palliative situation as they need to; they have the right to be sad, angry and feel afraid. They should ask all the questions they want, and try to get as much support from a professional as possible.

It's never easy to lose a loved one, and the lives of others are impacted in many ways. It is essential for them to heal after their loss. I keep in touch with families after the patient has passed on to make sure they are managing as well as can be expected. Families are often shaken by being involved in caring for a dying loved one, and the experience opens up the door to facing one's own mortality. I encourage family members to seek the help they need, whether supportive therapy, a well-deserved weekend away, a nurturing massage, or any other measure that can help them cope and heal.

For family members, moving on does not mean forgetting the dearly departed, it means taking care of themselves. Health care professionals can provide the best palliative care by understanding the emotional experiences of family members and offering the most support possible. ❖

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