Helpful Approaches to Palliative Care for Spiritual Carers

The World Health Organisation defines palliative care as:

Palliative care addresses the quality of life of people who have life- limiting illnesses and their families, by identifying, assessing and addressing physical, psychosocial and spiritual concerns; it does not attempt to either lengthen or shorten life (WHO 2008). Palliative care is also appropriate for those who are becoming frailer because of advanced age. Palliative care includes addressing the needs of people as they die along with providing bereavement support for families, with an emphasis on improved living

KEY FEATURES OF PALLIATIVE CARE:

a. Recognition and relief of pain and symptoms for the dying person
b. Inter-professional / multi-disciplinary team involved in care that may consist of doctors, nurses, interpreters, Chaplains and social workers
c. Recognition and relief through psychological and spiritual care
d. Appropriate care and support for carers, relatives and close friends
e. Sensitive communications between clinicians, patients, relatives and the chaplain or spiritual carer
f. Respect for truth and honesty in all dealings with the older person and relatives by clinicians, chaplains and spiritual carers

A PALLIATIVE CARE APPROACH:

a. Can reduce distress for an older person and his/her family (this may include physical, psychosocial, emotional, cultural or spiritual distress)
b. Reduce transfers to hospital because aged care staff develop skills to manage the palliative care needs of the older person
c. Help to encourage involvement of the older person and his/her family in decision making about their own care
d. Encourage open and early discussion about death and dying with improved advance care planning
e. Provide opportunities for improved control of pain and other symptoms to enable the person to be cared for by staff they know and trust
f. Enable spiritual carers to offer open access by listening for any questions around spiritual care from the person or their family
g. Provides appropriate care within each stage of the palliative care process and in particular, it offers emotional and spiritual support, as well as both comfort and care for an older person's distress at the end of life stage.

CULTURAL CONSIDERATIONS

Spiritual carers should not make assumptions about cultural needs based on a person's language, religion or country of origin. Some tips for getting it right:

a. Ask about relevant cultural aspects of caring for the person
b. Show respect by being aware of customs and cultural values
c. Respect that people have different reactions towards death e.g. for some Indigenous Australians, speaking the name of a deceased person can cause considerable stress
d. Communicate in ways that are appropriate e.g. avoid jargon and translate information into terms that the family and older person understand
e. Just because someone can understand spoken English does not mean they can automatically read it as well.
f. Check to see whether an interpreter is needed for the older person or family

SOME ATTITUDES HELPFUL FOR SUCCESSFUL PALLIATIVE CARE

a. **A caring attitude:**
   - involves sensitivity, empathy and compassion and demonstrates concern for the individual
   - shows concern for physical and mental, as well as spiritual and emotional aspects of an older person's care
   - brings a non-judgmental approach in which personality, intellect, ethnic origin and religious belief does not prejudice our spiritual care.

b. **Family and caregiver support**
   - be aware that relatives or carers of an older person who has a terminal illness may personally have considerable emotional and physical distress. This is especially true if they are caring for him/her at home. They may need emotional or spiritual care from the spiritual carer too.
   - palliative care, whether at home or in a hospital, often succeeds or fails depending on the care and support provided by carers or relatives.
   - family and caregiver support should be extended to bereaved families after the older person has died
   - Caregivers may require debriefing after death of the older person

END OF LIFE CARE PATHWAY

As a person approaches the end of their life the following may occur:

a. Rapid day to-day deterioration that is irreversible
b. A need for more frequent interventions
c. Semi-consciousness with lapses into unconsciousness. If the older person is being medicated for pain, this can be more noticeable
d. Increasing loss of ability to swallow and
e. Refusal to take food, fluid or medications orally and irreversible weight loss
f. An acute event that requires re-assessment and revision of treatment goals
g. Profound weakness
h. Changes in breathing patterns.

WHAT IS AN END OF LIFE CARE PATHWAY?

a. An end-of life care pathway acts as a road map to guide the care from doctors, nurses and care-workers in the last stage of a person's life. When someone commences the pathway, the following changes to their care may occur:
   - Non-essential medications are stopped and changes occur in how other medications are administered
   - Medication may be administered by injection or under the tongue instead of orally and medication may target pain, nausea, anxiety or breathing difficulties
   - Non-essential clinical interventions and observations are stopped e.g. blood pressure monitoring, weight checks and blood sugar monitoring
   - Special equipment may be organised e.g. a special pressure relieving mattress or other comfort aids.

b. Family members often spend many hours with the dying person. They may share with the spiritual carer their sadness and grief. They may ask questions about what is happening. It is okay to respond to these questions so long as they are within your scope of practice as a spiritual carer.

c. If you are unsure of what to say (or the questions are about clinical issues), reassure the family and tell them that you will ask the nurse to come and speak with them. If they relate to the funeral or pastoral issues, you wouldbe wise to see if the family would like a Chaplain to join them.

d. Older people and family members often become close to spiritual carers and may mention issues related to advance care planning with you. Sometimes what seems like a *throw away* comment e.g. When seeing an older person on life support, the visitor may say, *I wouldn't want to live like that* may be important to follow up. Ask the person or family member if they would like to talk to a nurse about their concerns. Be alert for any ongoing concerns the person may raise.

e. Some spiritual carers visit a dying person and are apprehensive about what they will see. Some want to help the person with advice or share their own experiences. They may see themselves as counsellors; or be there to help the person *be saved* before they die. Giving advice or being an evangelist is not at all helpful unless requested by the older person.

SPIRITUAL CARER ROLE

A spiritual carer has a distinctive role to play for the older person and their family. Be sensitive to ensure you are invited to be with people in this final stage of the older person's journey. Some practical issues to be alert to include:

a. Where possible, only have two people around the bed of a dying person at any one time. It is overwhelming for a person who is dying, if there are too many people
b. Make sure the person's particular faith tradition and cultural values have been respected
c. When an older person is referred to palliative care and there is a Chaplain, he or she is the spiritual leader. Advise him/her that you've been a spiritual carer to the older person. Partner with the Chaplain and introduce the older person and/or their family to him/her
d. There are real advantages for a hospital or care home to have a chaplain as part of the multi-disciplinary team
e. Spiritual and emotional support is as important as physical and mental support at end of life care
f. When completing the emotional/spiritual aspects of assessment or re-assessment for end-of-life-care, spiritual carers or Chaplains should complete this task rather than a clinician
g. Given that emotional and spiritual distress may increase near to an older person's death, ongoing assessment of spiritual and emotional care needs should be encouraged and implemented

SELF CARE

Close relationships can develop between spiritual carers and a resident. It is important to be aware that when a resident dies, you may grieve as well. You are not expected to be a robot, and it is possible that you may feel sad, angry, upset, confused, guilty or even relieved at this time. Feelings of grief are different for everyone and are a normal reaction to a loss. The following suggestions may assist you with your grief:

- Ask the family's permission to attend the funeral
- Talk to your supervisor or colleagues about how you are feeling
- Seek support from a professional counsellor, spiritual director/Pastor