

Chapter 34

PALLIATIVE AND END-OF-LIFE CARE



INTRODUCTION

Among all the medical advances and increased capability to cure in the last few decades, healthcare lost its way in relation to the fact that people do die and, when they die, they usually want a peaceful and dignified death, preferably at home with their family attending. In response to this not happening, palliative and end-of-life care have become very important and topical issues, particularly in regard to the management of death when it does not come about quickly and smoothly. Palliative and end-of-life care emerged from the realm of cancer care. However, in recent years the knowledge that has been developed in cancer care has been applied in the care of other non-malignant, terminal medical conditions (Parker et al 2005). This type of care recognises that the person is going to die, but the intention is to neither hasten nor postpone death. The focus is holistic care, with the goal of maximising quality of life through support for controlling distressing symptoms such as pain, managing psychosocial stressors and attending to a person's spiritual needs. The World Health Organization (2009) offers the following definition for palliative care:

Palliative care improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement.

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of care
- offers a support system to help people live as actively as possible until death
- offers a support system to help the family cope during the person's illness and in their own bereavement
- uses a team approach to address the needs of people and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness, and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

End-of-life care refers to the care given in the last few weeks of life. Palliative and end-of-life care typically extend to include significant others and can be delivered in the older person's home. If the older person can no longer be cared for at home, it could be in a hospice, hospital or residential aged care facility (RACF).

THE ROLE OF THE MENTAL HEALTH WORKER

Zarit and Zarit (2007) assert that mental health workers are in a unique position to address palliative care and end-of-life issues. This strong position comes about through our ability to develop a therapeutic relationship. Palliative care specialists have written extensively about the primacy of the therapeutic relationship in palliative care (Canning et al 2007). By already knowing what beliefs, attitudes and values an older person holds, the mental health worker can help maintain dignity, and support decisions that are consistent with these beliefs, attitudes and values. Although mental health workers have a strong focus on psychological and emotional needs, addressing physical needs should not be overlooked and certainly come under the role of being a mental health worker. This could mean assessing physical needs and, if required, arranging for them to be met by the appropriate people.

MENTAL HEALTH ISSUES

Palliative and end-of-life care and mental health issues can be examined from two perspectives. Firstly, older people who are terminally ill often experience depressive symptoms, and chronic/terminal illness is a recognised risk factor for depression. Secondly, older people who have a chronic mental illness may require palliative/end-of-life care. This may include an older person with dementia, an older person who has taken high doses of antipsychotic medications all their life, an older person with chronic schizophrenia which has eroded personality, social skills and the ability to manage health in relation to smoking and obesity, and an older person with substance-abuse problems.

Around 30% of people receiving palliative care are reported to be depressed and many feel anxious concerning what may be the outcomes of their illness (Hotopf et al 2002). In describing the experience of getting old and sick, Clarke (2007) suggests breaking down depression into three components:

1. demoralisation, where the ongoing helplessness leads to feelings of hopelessness, diminished capacity or competence, reduced self-esteem and a reduced sense of meaning and purpose in life to the extent where there is a loss of will to live and a desire to hasten death
2. grief, where there is a deep sense of loss and sorrow, and
3. anhedonic depression, where there is a profound loss of pleasure and, therefore, loss of interest in all things and matters.

The breaking down of a diagnosis of depression into these psychological elements will assist in understanding what feelings the older person is experiencing and enable more effective targeting of interventions. The pharmacological and non-pharmacological treatment for depression is covered comprehensively in Chapter 20. Antidepressants, at levels subtherapeutic for depression, are an effective treatment for neuropathic pain and this is something a mental health worker could reasonably expect to encounter (Carr et al 2002). In addition to the standard treatments for depression, older people

in a palliative/end-of-life situation require sound and timely information and to be involved as much as possible in the decision-making processes.

Grief and bereavement are normal human responses and they should be allowed to run their natural course. Grief can be felt at many and various times throughout the dying process, however long it takes. The older person who is dying can experience grief as well as their significant others. Grief is the response to loss and the dying person can have many losses to deal with (e.g. loss of function, control, independence and eventually loss of life). Anticipatory grief is the grief that is felt at diagnosis where a person can almost predict what their future will entail. It is during this time that many decisions concerning the future can be made. Normal and uncomplicated grief involves what would be a person's expected responses to a loss, expressed physically and/or psychologically. The signs of grief are many, but usually include crying, anorexia, lack of initiative, organisational ability and energy, inability to sleep, feelings of emptiness, questioning faith systems and soul searching. Such responses are characterised and shaped by past experiences with loss and death, and social and cultural factors.

Complicated grief occurs when the grieving period is exceptionally long (>3 months), or when there are no signs that the symptoms are resolving or the symptoms are getting worse, or when the grief interferes severely with the person's daily functioning. Complicated grief requires active intervention by a mental health professional. Bereavement applies to the ones who will be left mourning after the person has died. Bereavement care can begin before the death of the person. This is usually done to try and prevent complicated grief and bereavement.

Grief and bereavement therapy are well addressed in the literature and there are some therapists who have specialised in this field (Worden 1996). There are three main principles that are followed. The first principle is to promote emotional expression via empathetic responses. Emotions can vary from intense sorrow for losses to anger for being afflicted with the disease. The second principle is based on an understanding that people who are grieving may go through stages of denial and avoidance. These are negative defence mechanisms that need to be challenged in a gradual and gentle way to enable the person to realise the gravity of the situation so they can adjust to it. The third principle is that people need time to adjust and make sense of what is happening to them. This comes about by spending the therapy time discussing, listening and thinking through the issues that are bothering or concerning them.

Some people are prepared to face their mortality and others are not. According to Abbey (2001), it is important to determine how the older person feels about dying and how they may want to die. As a younger person, they may have said things like, 'Shoot me if I get like that' (in the case of dementia or some other incurable debilitating disease). However, as people get older, this certainty about not wanting to prolong their life can become less intense, although they may not want to suffer unbearably. In the case where people are prepared to face their mortality, there may be an option to plan end-of-life care well ahead of time, usually in the months leading up to death, rather than in the last few days when it may become more of a crisis situation.

In Australia, there are options for people to make an 'advance directive', where a competent older person can stipulate who will be their substitute decision maker if they want to be resuscitated or mechanically ventilated or have any other life-prolonging device used on them. These directives protect the right of the older person to make decisions about their care in the terminal phase, and it removes some of the burden a family may have to grapple with in the face of such difficult decisions. A device regarding advance

directives can be obtained from the office of the Adult Guardian. Another option is to appoint a power of attorney for health to act on the person's behalf. Each state and territory in Australia has different legislation pertaining to these matters, and it is beyond the scope of this chapter to go into that level of detail, but it would be a sensible approach to be familiar with what options are available in the relevant jurisdiction.

THE OLDER PERSON AND FAMILY ASSESSMENT

The purpose of assessment in palliative/end-of-life care is to identify areas of concern for the older person and their family, so plans can be formulated to meet their needs. There are a number of tools available to assist with this activity and they usually cover the essential areas of diagnosis, treatment, history of illness, physical assessment, psychosocial and spiritual assessment, and capacity/competency assessment (Parker & McLeod 2002). All of these elements have been discussed in detail in other chapters in this book. One difference is that when assessing palliative/end-of-life care, anticipatory planning for death may also be included (Doran & Geary 2005). Within palliative care, family case conferences are often used as a forum to make explicit the desires of the older person. These conferences include the relevant health professionals, such as case managers, the general medical practitioner and the mental health worker. In recent times, palliative care has become a specialty, and if such a service is available and appropriate to the older person's assessed needs, it would be very beneficial to have such expertise at hand.

Palliative care and end-of-life care have many ethical dilemmas surrounding them. The older individual or a family member may seek the advice of a mental health worker in regard to strategies that may extend a person's life. Percutaneous endoscopic gastrostomy (PEG) feeding is one such example. In these situations, the mental health worker must maintain a professional approach, which can be difficult when one may have gotten to know the family very well. The rules of informed decision making come into play here by ensuring the people involved have all the available information given to them in a format that they can understand. The mental health worker must be aware of their values and biases and ensure these do not impact on the decision. Additionally, an older person may have to be assessed for delirium, depression and anxiety, as these conditions can cloud the decision-making process (Zarit & Zarit 2007).

DEATH AND DYING

Many healthcare workers find it difficult to tell a person they are dying. Hancock et al (2007) conducted a systematic review relating to truth-telling in discussing prognosis with people with progressive, advanced life-limiting illnesses and their carers. Reasons for the healthcare worker's discomfort included perceived lack of training, stress, no time to attend to the person's emotional needs, fear of a negative impact on the person, uncertainty about prognostication, requests from family members to withhold information, and a feeling of inadequacy or hopelessness regarding the unavailability of further curative treatment. However, the authors have also identified studies suggesting that people can discuss the topic without it having a negative impact on them.

In 1970, Kubler-Ross published an influential text on death and dying where she set out the stages a person goes through when they are dying. Nowadays, palliative care experts tend not to use her stages and there are many other theories regarding the

responses of people who learn they are to die soon. Either way, to offer meaningful support to a dying person, it is important to know what they may be experiencing, although in some instances it is difficult to predict prognosis and therefore going through 'stages' may be problematic. Kubler-Ross is a starting point and her stages of dying are denial, anger, bargaining, depression and acceptance. A person may not experience all of the stages or go through them sequentially; however, no matter which stage, it is important to always remain accepting, supportive and non-judgmental in all interactions.

Initially, the older person may deny that they are dying and reject any attempts that may support this notion, such as preparing a will or advance directive. The next stage is anger where the person may ask questions (e.g. Why me?). This anger may be displaced at other people or objects and it is important to let people know the reason behind such behaviour. In this stage, the older person may withdraw and become more dependent. Following anger is the bargaining stage where a person may attempt to change their fate by bargaining, usually with a higher being such as 'God'. From the bargaining stage, the older person may experience depression. Thoughts in relation to dying and death can come out and the mental health worker needs to be prepared to talk about these in a sensitive but matter-of-fact manner, and to call on further assistance if required. The last stage is acceptance, where the person accepts that they are dying. In this stage, they may need to be in contact with various people so that they can put their affairs in order and say goodbye.

SUMMARY

This chapter has examined an issue that many older people and mental health workers alike find difficult to address—death and dying. Compassionate care and support of death is a skill that has been lost among the many recent medical advances that have focused on cures and prolonging life. Palliative care and end-of-life care have emerged as special areas to give guidance so that older people can have peaceful and dignified deaths that respect their wishes as much as possible. It is recognised that the inherent skills of a mental health worker can play an important role in facilitating this process, particularly in regard to the management of depression and grief that older people and their caregivers can experience during the end phase of life.

FURTHER READING

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USEFUL WEBSITES

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- CareSearch: www.caresearch.com.au
- National Health and Medical Research Council: www.nhmr.gov.au/PUBLICATIONS/synopses/_files/pc29.pdf
- National Institute for Health and Clinical Excellence: www.nice.org.uk/uid6/CG42

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