Principles for Palliative and End-of-Life Care in Residential Aged Care

Introduction

These principles have been developed collaboratively by Palliative Care Australia, Alzheimer's Australia, COTA Australia, Aged & Community Services Australia, Leading Age Services Australia, Catholic Health Australia and the Aged Care Guild to present a united commitment in recognising the diverse needs of residential aged care consumers, families, carers, aged care staff and service providers in providing palliative and end-of-life care.

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LEADING AGE SERVICES
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The voice of aged care

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The Australian population is ageing and the need for palliative and end-of-life care across all care settings is increasing. As the population ages, so too does the demand for aged care in both the home and in residential care settings.

In 2010–11, 75% of the 116,481 people aged at least 65 years who died in Australia had used aged care services in 12 months before their death. The older a person was when they died, the more likely they were to have been accessing a service at the time of death.[1]

It is important that older people are supported to receive high quality end-of-life care in the setting of their choice, whether that be in their own home, in residential aged care, in an acute care hospital or in a dedicated hospice service. Many people receive palliative care in an acute care hospital, but there is a growing recognition that acute care hospitals are not always the most appropriate settings from which to provide dedicated end-of-life care that promotes comfort and quality of life.

Nationally there were 231,500 permanent residents in Australia in 2014–15 with completed ACFI appraisals, yet only 1 in 25 of these indicated the need for palliative care.[2]

Ensuring the availability of high quality palliative and end-of-life care services in aged care facilities and people's own homes, will enable more older Australians to have a good death, better support their families and carers during the dying and bereavement processes and facilitate the better allocation of scarce health resources.

The principles draw upon the *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care* (The National Consensus Statement) developed by the Australian Commission on Safety and Quality in Health Care, particularly:[3]

- Dying is a normal part of life and a human experience, not just a biological or medical event
- Patients must be empowered to direct their own care, whenever possible. A patient's needs, goals and wishes at the end of life may change over time
- Providing for the cultural, spiritual and psychosocial needs of patients, and their families and carers is as important as meeting their physical needs
- Recognising when a consumer is approaching the end-of-life is essential to delivering appropriate, compassionate and timely end-of-life care.

Palliative and end-of-life care delivered in accordance with these principles will help older Australians in residential aged care to have the best death possible, and to live the remainder of their lives to the fullest with dignity and in comfort. It will also support families and carers in caring for their loved one and during the bereavement period and support staff to deliver the best care possible.

The principles reflect the need to:

- recognise when an aged care consumer is approaching the end of life
- assess, document and meet changing care requirements
- ensure equitable access to high quality end-of-life care
- ensure residential aged care services are adequately resourced to provide high quality palliative care
- ensure staff are adequately trained and supported in delivering end-of-life care
- ensure care is holistic and seamless
- respect dignity, privacy and diversity, including spiritual, cultural and gender diversity.
- understand and meet the needs of consumers with dementia
- support families and carers in bereavement
- appropriately acknowledge the contribution of the consumer.

> ***Take care with the end as you do with the beginning.***[4]

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1. AIHW 2016, Palliative care in residential aged care. 2. AIHW 2015, Use of aged care services before death, Data Linkage Series Number 19.
3. *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care*, Sydney, ACSQHC, 2015, p.4.
4. Attributed to Lao Tzu, quoted in A matter of life and death – 60 voices share their wisdom, Rosalind Bradley, Jessica Kingsley Publishers, 2016.

Principles

The following principles reflect the views of Palliative Care Australia, Alzheimer's Australia, COTA Australia, Aged & Community Services Australia, Leading Age Services Australia, Catholic Health Australia and the Aged Care Guild .

1

Consumers physical and mental needs at end-of-life are assessed and recognised

a. End-of-life care should be recognised as part of the normal scope of practice of residential aged care, acknowledging that aged care facilities are home for many people at the end-of-life.

b. All care is consumer and family centred and directed.

c. The end-of-life needs of residents of aged care services are assessed, documented and regularly reviewed.

d. The stages of life-limiting conditions are recognised, with end-of-life care needs acknowledged as requiring a palliative approach.

e. Changes in consumer health status are recognised and changing needs documented and met.

f. The mental health needs of consumers are assessed, documented and met including treatment for anxiety or depression if required.

2

Consumers, families and carers are involved in end-of-life planning and decision making

a. Consumers, families and carers are kept regularly informed of the stages of the life-limiting condition and treatment options and supported through treatment decisions if circumstances change.

b. Consumers, families and carers are supported to develop and regularly review advance care plans, particularly if circumstances change.

c. Consumers are supported to regularly discuss and understand the implications of treatment options and different end-of-life care choices, with their needs and wishes documented.

d. Consumers, families and carers are supported to change advance care plans or treatment decisions if circumstances change. Consumers, families and carers understand their right to request or decline life-prolonging care.

e. Consumers understand that unless required by law, doctors are not obliged to initiate or continue treatments that will not offer a reasonable hope or benefit or improve the patient's quality of life.[5]

f. Where appropriate, substitute decision makers are identified and actively involved in discussing the consumer's needs and wishes.

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5. Op.Cit (3), p5.

3

Consumers receive equitable and timely access to appropriate end-of-life care within aged care facilities

a. Consumers are able to access appropriate palliative care support, regardless of income, background, diagnosis, prognosis or geographic location.

b. Consumers receive adequate and timely pain and symptom management.

c. Consumers and staff have access to appropriate equipment to support end-of-life care and manage symptoms.

4

End-of-life care is holistic, integrated and delivered by appropriately trained and skilled staff

a. End-of-life care is considered a core competency for aged care workers.

b. End-of-life care is delivered by appropriately trained and skilled staff and teams.

c. All staff with a caring role are trained and supported to recognise when end-of-life care is required and a consumer's needs have changed.

d. Residential aged care services are adequately resourced to deliver and/or support the delivery of end-of-life care. This includes access to specialised equipment and materials.

e. Staff actively develop and document care plans and a care leader is identified to ensure care is appropriate, in accordance with the consumer and family wishes, coordinated and holistic.

f. All residential aged care services have access to specialist palliative care support when required. We recognise that this is a particular challenge for rural and remote locations.

g. The roles of all those involved in end-of-life care are recognised, respected and supported, including specialist palliative care, general practitioners, primary health care, pharmacists, nurses, care staff, support and services staff, volunteers and those providing social and spiritual support.

h. Staff in residential aged care services are appropriately supported in caring for consumers with life-limiting conditions.

i. Transfers to other services are based on necessity or consumer/carer choice, with care plans shared.

5

The end-of-life care needs of consumers with dementia or cognitive impairment are understood and met within residential aged care

a. Dementia is recognised as a terminal illness.

b. Where possible, staff will encourage and support end-of-life care planning and decision-making with early involvement of the consumer, family and carers at the time of a dementia diagnosis.

c. Residential aged care services will provide appropriate care to consumers with behavioural and psychological symptoms of dementia or cognitive impairment, ensuring all appropriate services including end-of-life care are identified, documented and accessed.

d. Substitute decision makers are actively involved in discussing the consumer needs and wishes.

6

Consumers, families and carers are treated with dignity and respect

a. Consumers are treated with dignity and respect throughout end-of-life care, including after death.

b. Consumers, families and carers have their need for privacy respected, including after death.

c. Families, carers and friends are supported to spend as much time with a loved one as they wish, including after death.

d. Intimate care needs are attended to regularly and with respect to the consumer and their family and carers.

e. Consumer possessions are appropriately cared for and returned to family (or as directed by the consumer) in a timely manner after death.

7

Consumers have their spiritual, cultural and psychosocial needs respected and fulfilled

a. Residential aged care services respect diversity and provide end-of-life care that meet the needs of consumers, including those from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander peoples and people who identify as lesbian, gay, bisexual, transsexual or intersex.

b. Spirituality, defined as 'the way we seek and express meaning and purpose; the way we experience our connection to the moment, self, others, our world and the significant or sacred'[6] is discussed with consumers and families, and consumers and families are supported in having those needs met.

c. Cultural needs are discussed with consumers and families, and consumers and families are supported in having their needs met.

d. In alignment with the values of the Compassionate Communities movement,[7] consumers, families and carers are supported in identifying and maintaining caring networks.

e. Consumers are offered support to document key aspects of their lives, to reflect their contributions and chart a 'life story'.

f. As far as is practical, consumers are encouraged to identify and fulfil last wishes and goals.

8

Families, carers, staff and residents are supported in bereavement

a. Families and carers are supported to care for and/or stay with, a loved one after death.

b. Spiritual and cultural needs following death are understood and respected and families and carers supported in undertaking death and grief related practices and rituals.

c. Families and carers are offered support in grief and grieving, or referred to appropriate support services.

d. Staff and other residents of aged care services are appropriately supported in loss and grief.

> *Residential aged care services and staff should take the appropriate steps to recognise and acknowledge the consumer's life and contribution after their death.*

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[6] Meaningful Ageing Australia, Definitions, http://meaningfulageing.org.au/definitions. [7] Compassionate Communities aims to promote and integrate social approaches to dying, death and bereavement in the everyday life of individuals and communities. http://www.compassionatecommunities.net.au/#ccn.

Definitions

The World Health Organisation[8] defines palliative care as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- 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.

The World Health Organisation also states:

Addressing suffering involves taking care of issues beyond physical symptoms.

Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death.

Palliative care is explicitly recognised under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals.

The *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care*[9] states that people are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive and incurable conditions
- general frailty and co-existing conditions that mean that they are expected to die within 12 months
- existing conditions, if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.

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[8] World Health Organization Fact Sheet No 402, Palliative Care, July 2015. [9] Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care*, Sydney, ACSQHC, 2015, p33.