2018

CONSENSUS STATEMENT

Carer and Consumer Engagement in Palliative Care and End-of-Life Care

PalliativeCare AUSTRALIA

CHF Consumers Health Forum OF Australia

Carers Australia

Introduction

This consensus statement has been developed by Palliative Care Australia, Consumers Health Forum of Australia and Carers Australia. Palliative care and end-of-life care should be strongly responsive to the needs, preferences and values of people, their families and carers. People should be able to access appropriate palliative care support, regardless of income, background, diagnosis, prognosis; they should be able to access palliative care when and where they need it.

Palliative care is an all-inclusive approach to improving the quality of life for people living with a life-limiting illness, their families and carers. This involves:

① early intervention to prevent or relieve pain and other distressing physical symptoms (such as breathing difficulties, nausea, vomiting and delirium).

② the provision of psychological and spiritual support to reduce suffering and distress related to feelings of helplessness, remorse, loss, anxiety and loneliness as people and their families face mortality.

③ social support to address practical and financial issues related to the person's social and living circumstances, access to carers and their functional independence.

The individual needs of people who are living with a life-limiting illness, their carer and family will determine which services they access at any given time.

This Statement draws upon the *National Consensus Statement: Essential Elements for Safe and High Quality End-of-Life Care* developed by the Australian Commission on Safety and Quality in Health Care[1] and the *National Palliative Care Standards*[2] developed by Palliative Care Australia.

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1. *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care*, Sydney, ACSQHC, 2015.
2. National Palliative Care Standards, Canberra, PCA, 2018

Consensus Statement

Person and Family Centred Care

- A person and family-centred approach to palliative care and end-of-life care accepts that an illness has an impact on both the individual and their family and carers.
- The focus of care should be on the individual and the family unit. This requires effective communication, supported or shared-decision making and respect for personal autonomy
- People must be empowered to direct their own care whenever possible, as the more choice and control a person has over their own health and care the better the outcomes. This includes people with dementia and other types of cognitive impairment.
- Care should reflect people's changing priorities, needs, goals and wishes over the course of their illness and as they approach death.
- Many factors may shape or change a person's preferences about where their treatment and care occur. Changes in family circumstances, such as the poor health or loss of carers, may reduce the possibility of receiving palliative care or end-of-life care at home.
- Consumers must be treated with dignity and respect, their need for privacy considered and the right for regular personal care needs maintained, throughout palliative care and end-of-life care, including after death.
- Families, carers and friends should be supported to spend as much time with a loved one as they wish, including after death.

Carers need support

- The extent and quality of support provided to the carer and the person nearing the end of life is key to the experience they both have. Caring for someone who is dying is an individual commitment and can be a rich, rewarding and challenging experience.
- There is often a heavy emotional strain associated with caregiving at the end of life, with carers experiencing fatigue, resentment, social isolation and stress.
- Carers need support to allow them to provide care in a manner that also promotes their health, wellbeing and personal aspirations. These include:
    - improved access to timely in-home support (including services, equipment, information, education and resources)
    - expanded access to planned and emergency respite care services to support carers
    - early identification of carers' emotional and physical health needs, including during bereavement
    - addressing carers' needs for greater financial support, including prompt access to the carers allowance, and
    - carer-sensitive workplace policies that support flexible working hours and leave arrangements for carers of people receiving palliative care or end-of-life care
- Young carers[3] caring for a person receiving palliative care may need additional support in accessing services for themselves and for those they are caring for. This includes school support to ensure that their education needs are being met, enabling access to training and employment opportunities and participation in key social networks.

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[3] Young carers are people under 25 years of age.

Community, culture and beliefs

- Health and care delivery must not be impeded by cultural barriers, power imbalance or knowledge/information differences between those receiving and those delivering care.
- Providing for cultural, spiritual and psychosocial needs of people, and their families and carers is as important as meeting their physical needs.
- Dying is a normal part of life and a human experience – not just a medical event. The whole community is responsible for normalising discussions about advance care preferences, death and dying.
- Spiritual and cultural needs and preferences in relation to death and grief practices must be respected.
- Services need to 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.
- In line with the values of the Compassionate Communities movement,[4] consumers, families and carers are supported to identify and maintain caring networks.

Responsive care delivery

- Health and care services need to be shaped by, and respond to, community values and priorities. People should be viewed as partners in their own care.
- Co-design should be standard practice, where consumers serve as equal contributors to work with policy makers, commissioners of services and service providers during review, planning and implementation.
- Improved respite services are urgently needed that can be responsive to, and provide the type of care required, of a person receiving palliative care or end-of-life care.
- Health and care service staff should recognise deterioration of carers health and well-being so this care is not overlooked.
- Health and care services must have access to appropriate equipment to support end-of-life care and manage symptoms, with all people able to receive adequate pain and other symptom management.
- Palliative care and end-of-life care should be delivered by appropriately trained and skilled staff and teams, including volunteers. All staff with a caring role must be trained and supported to recognise when a person's needs have changed.
- All services should have access to specialist palliative care support when required. This is a challenge for rural and remote locations and may need innovative solutions.
- The roles of all those involved in end-of-life care need to be recognised, respected and supported. This includes specialist palliative care, general practitioners, pharmacists, nurses, care staff, support and services staff, volunteers and those providing social and spiritual support.
- Transfers to other services should be informed by need and consumer/carer choice and always discussed with the consumer/carer. Transfers should always be coordinated to ensure continuity of care, including needed support for carers.

Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life. Dying is a normal process with palliative care offering a support system to help people to live their life as fully and as comfortably as possible until death and to help families cope during this illness and in their bereavement.

People are approaching the 'end of life' when they are likely to die within the next 12-months.

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[4] 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/#ccns

Contact

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