Palliative Approach in the Aged Care Setting

2020

1. Overarching principles

1.1. Australia's population is ageing. Although people are living longer, for those living with life limiting illnesses[1] such as dementia, disease progression is gradual and irreversible. The role of health and aged care systems should be to ensure the best possible quality of life for older people with a life limiting illness.

1.2. Ensuring dignity of life and death through adequate provision of palliative care to all members of the community who require it is recognised by the World Health Organisation under the human right to health[2].

1.3. A palliative approach to providing care affirms life and respects dying as a normal process. It intends neither to hasten nor postpone death but rather aims to enhance quality of life while also positively influencing the course of illness.

1.4. Acute medical care in Australia prioritises treating disease and preserving life. Acute care does not always deliver the best outcomes for older people with life limiting illnesses and can impose additional needless pain and distress without necessarily delivering desirable outcomes.

1.5. Older people with a life-limiting illness have a right to timely, comprehensive, and appropriate palliative care services when required, from diagnosis, as their illness progresses, and the final days when they are approaching the end of life.

1.6. Palliative care should be provided in all aged care settings, including residential aged care, home care and respite care and, as much as possible, enable people to be cared for and die at the place of their choice.

1.7. The aim of a palliative approach in the aged care setting is to maximise quality of life for older persons and their families through appropriate needs-based care, reducing an individual's symptoms and distress through early identification, assessment and treatment of pain, physical, cultural, psychological, social, and spiritual needs. A palliative approach should provide the older person with:

(a) autonomy, dignity, comfort and respect;
(b) an honest, open discussion about conditions and treatment options;
(c) choice in available evidence-based treatment options;
(d) effective management of pain and other distressing symptoms;
(e) quality of life, as defined by the patient, in the circumstances;
(f) their cultural or spiritual wishes honoured; and
(g) access to the people they wish to be present.

1.8. Greater community, patient and carer awareness and understanding of palliative care, its aims, outcomes and benefits for older people is required to alleviate any potential fears and misunderstandings in the community, and to increase appropriate resourcing.

[1] **Life limiting illness** - An illness that can be reasonably expected to cause the death of the patient within a foreseeable future.
[2] WHO (2018) *Palliative Care*

2. Role of the medical practitioner

2.1. Medical practitioners, in particular general practitioners (GPs), play a central role in implementing palliative care in all aged care settings. GPs are involved in holistically managing, prescribing and making timely treatment decisions for people with a life limiting disease.

2.2. Medical practitioners have an ethical duty to care for older people with life limiting illness so that death can occur in comfort and dignity.

2.3. Doctors should understand that they have a responsibility to initiate and provide good quality end of life care which:

(a) Strives to ensure that a dying patient is free from pain and suffering; and
(b) Endeavours to uphold the older person's values, preferences and goals of care.

2.4. The AMA supports a palliative approach that is delivered by a multidisciplinary team. Such teams should be led by GPs and include, but not be limited to nurses and allied health professionals working together to address an older person's physical, psychological and spiritual care objectives.

2.5. By acknowledging that the goals of curative treatment in acute care settings and palliative care are usually different, medical practitioners can ensure that an older person receives a palliative approach and appropriate therapies.

2.6. Palliative care should be provided based on need rather than diagnosis alone. Where possible and appropriate, a palliative approach should limit distressing interventions such as unnecessary hospitalisation, by providing care in-situ.

2.7. It is important that palliative care strategies for patients are developed early to address issues of pain management and symptom relief. Strategies should also consider the patient's spiritual and cultural needs.

2.8. Aged care providers in both residential and home care settings have a duty to work with medical practitioners, particularly GPs, in applying the palliative care approach. By working together with GPs, they ensure that older people are receiving the best possible palliative care that is adapted to their requirements and respects their health, spiritual and cultural needs.

2.9. Medical practitioners play an important role in increasing patients' and broader community understanding of palliative care. They have a duty to their older patients, their families and aged care providers to explain the palliative care approach, its objectives, outcomes and benefits.

3. Palliative care planning

3.1. GPs play a central role to care planning for their patients. As older people move through different types of aged care service provision, depending on their need, their continuity of care is ensured by their ongoing relationship with their GP.

3.2. Palliative care can be planned in different contexts, including through aged care plans, advance care planning and developing Advance Care Directives (ACD). It is the AMA view that advance care planning should be central to the provision of person centred, individually tailored palliative care.

3.3. The AMA supports advance care planning and older people entering or accessing aged care services developing their own ACDs.

3.4. Through the process of planning their care and documenting their wishes in ACDs older people can ensure that their dignity is respected and that they receive quality end of life care that they wish, in a manner that they wish and in the setting of their choosing where possible. This includes their wishes and preferences for hospital transfer at times of acute care need.

3.5. Palliative care planning through ACDs may be particularly important for people living with dementia who are accessing aged care services. Formal prior delegation of authority and an advance care plan should be sought whilst the older person has decision-making capacity and should be regularly reviewed.

3.6. When an older person loses decision-making capacity, the views of family or a legally recognised substitute decision-maker should be sought to ascertain the wishes of the older person. For many, the loss of decision-making capacity is progressive rather than immediate and may fluctuate over time. Such persons should be encouraged to participate in treatment decisions consistent with their level of capacity at the time a decision needs to be made.

3.7. When a person has developed a formal ACD, that ACD should be shared among all those involved in their care, including:

(a) Family, informal carers and substitute decision maker.
(b) Their GP and hospital providing acute health care.
(c) The provider of aged care services and staff involved in their care.
(d) Anyone else the older person deems appropriate.

3.8. Advance care plans should be reviewed as the patient's condition, and possibly treatment preferences, change. Any changes to an advance care plan should by communicated those listed above.

3.9. The AMA believes that My Health Record (MHR) provides a unique opportunity to ensure that an older person's ACD is known to all involved in their care and respected in the care process. It is particularly relevant for the provision of palliative care as it enables the upload and storing of health directives as well as easy access to all health professionals involved in the older person's care.

4. Training in palliative care

4.1. Everyone involved in palliative care in the aged care setting should be adequately trained for the provision of that care, including GPs, nursing staff, allied health professionals and personal care attendants.

4.2. While training for medical professionals differ to those of other staff involved, there are some common subjects that should cover all those involved. They include:

(a) Recognising signs of deterioration in older people and increasing palliative care needs that require further specialist assessment, including by Specialist Palliative Care services.
(b) How to talk to the patient and their family members about the diagnosis and the need for palliative care.
(c) Managing conflicts and stressful situations with people who are receiving palliative care, their family members and carers.
(d) Bereavement care.
(e) Resilience mechanisms for coping with death and dying of patients.
(f) Providing social and spiritual support for dying older people.
(g) Cultural, religious and spiritual aspects of palliative care.

5. Palliative care in the home care setting

5.1. The AMA believes that older people have the right to receive palliative care in their home if that is the place of their choosing.

5.2. Palliative care provided at home should be part of the home care received through the Government subsidised home and community care package programs. This care should be individually tailored for each patient, catering for their individual diverse needs. It should include, but not be limited to, nursing care, personal care, domestic assistance and emotional support and counselling.

5.3. The AMA supports continuity of care in palliative care, meaning minimising the turnover of staff caring for the older person with a life-limiting illness at their home, including the person's usual GP, nurses and personal care workers.

6. Palliative care in residential aged care facilities

6.1. It should be mandatory that all residential aged care facility (RACF) residents have a current ACD.

6.2. The AMA believes that older people have the right to receive palliative care and to die in the RACF they are residing in, if that is the place of their choosing.

6.3. Therefore, adequate funding to provide quality palliative care must be built in to any RACF funding model by defining the skills and staff requirements and recognising that palliative management is a basic RACF service.

6.4. The RACF funding model must be flexible enough to account for increased needs at the end of life and be responsive enough to allow for reassessment when required.

6.5. Ensuring that comprehensive palliative care services are provided in RACFs will reduce unnecessary hospital transfers and admissions and ultimately reduce the cost of care while at the same time respecting the older person's known wishes and preferences.

6.6. The older person's usual GP should be central to provision and coordination of palliative care in the RACF setting.

6.7. RACFs must be appropriately equipped to support medical practitioners' access to patients and their files, allow a palliative approach to be provided effectively and at the earliest opportunity.

6.8. RACFs need to be adequately staffed with the right skill mix available to provide quality care at all hours for patients needing palliative care, including staff qualified to administer pain and palliative care medications.

6.9. The AMA upholds that RACF care staff should be trained in providing palliative care and that there should be regular training refreshers for the provision of palliative care. Palliative care provided in a RACF should be individually tailored for each patient, catering for their individual diverse needs.

See also:

AMA Position Statement on Resourcing Aged Care 2018
AMA Position Statement on Medical Care for Older People 2020
AMA Position Statement: Health and Care of Older People 2018
AMA Position Statement on End of Life Care and Advance Care Planning 2014
AMA Position Statement Euthanasia and Physician Assisted Suicide 2016