



## Guidelines for a palliative approach for aged care in the community setting: A suite of resources

Christine Toye<sup>1,2,3</sup>, Scott Blackwell<sup>4,5</sup>, Sean Maher<sup>1,2,3</sup>, David C. Currow<sup>6</sup>, Kristi Holloway<sup>1,7</sup>, Jennifer Tieman<sup>6</sup>, Meg Hegarty<sup>6</sup>

1. Curtin Health Innovation Institute, Curtin University; 2. Edith Cowan University; 3. Sir Charles Gairdner Hospital; 4. Palliative Care Australia; 5. Collaborative Primary Health Care WA; 6. Flinders University; 7. Hall and Prior Community Aged Care

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### BRIEF REPORT

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#### Corresponding Author:

Dr Christine Toye  
Associate Professor  
School of Nursing & Midwifery  
Curtin University, GPO BOX U1987  
Perth, Western Australia 6845  
[Email: c.toye@curtin.edu.au](mailto:c.toye@curtin.edu.au)

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### Abstract

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In Australia, many people ageing in their own homes are becoming increasingly frail and unwell, approaching the end of life. A palliative approach, which adheres to palliative care principles, is often appropriate. These principles provide a framework for proactive and holistic care in which quality of life and of dying is prioritised, as is support for families. A palliative approach can be delivered by the general practitioner working with the community aged care team, in collaboration with family carers. Support from specialist palliative care services is available if necessary.

The *Guidelines for a Palliative Approach for Aged Care in the Community Setting* were published by the Australian Government Department of Health and Ageing to inform practice in this area. There are three resource documents. The main document provides practical evidence based guidelines, good practice points, tools, and links to resources. This document is written for general practitioners, nurses, social workers, therapists, pastoral care workers, and other health professionals and responded to needs identified during national consultation. Evidence

based guidelines were underpinned by systematic reviews of the research literature. Good practice points were developed from literature reviews and expert opinion. Two 'plain English' booklets were developed in a process involving consumer consultation; one is for older people and their families, the other for care workers.

The resources are intended to facilitate home care that acknowledges and plans for the client's deteriorating functional trajectory and inevitable death. At a time when hospitals and residential aged care facilities are under enormous pressure as the population ages, such a planned approach makes sense for the health system as a whole. The approach also makes sense for older people who wish to die in their own homes. Family needs are recognised and addressed. Unnecessary hospitalisations or residential placements and clinically futile interventions are also minimised.

#### Key Words

Evidence-based health care, guidelines, palliative care, aged care, community care.

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#### What this study adds:

At a time when Australia's population is ageing, the relevance of palliative care to older people whose health is failing merits urgent consideration. Palliative care:

- is appropriate in malignant and non-malignant life limiting disease;
  - aims to enhance the quality of both life and dying using a holistic, planned approach;
  - is appropriate throughout the illness trajectory, based upon complexity of needs;
  - does not attempt to either lengthen or shorten life; and
  - supports the family.<sup>1</sup>
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#### Introduction

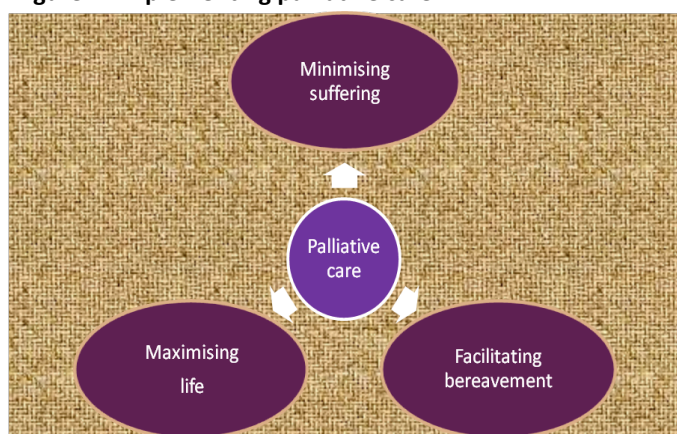
Specialist palliative care services have traditionally focused mainly on malignant disease.<sup>2,3</sup> These services provide

intermittent or ongoing care and address complex care needs.<sup>3</sup> A palliative approach, adhering to the same key tenets, can be delivered by the general practitioner working with the aged care team, in collaboration with any family carers, and with support from specialist palliative care services when needed.<sup>4</sup> In Figure 1, the woven background symbolises the three integrated dimensions of palliative care (physical, psychosocial, and spiritual) addressing 'maximising life', that is, the quality of life of the person; minimising their suffering; and facilitating bereavement in family and friends.

Evidence based guidelines informing the delivery of a palliative approach within Australian residential aged care facilities were published in 2006.<sup>4</sup> However, as emphasised in recent policy initiatives, sustainable approaches to care for older Australians need to include enhancing home care services, supporting informal carers, and ensuring better links between aged care and other health care systems.<sup>5</sup>

Home-based, long-term care for older people whose health is severely compromised because of life-limiting conditions generally occurs within the context of aged care packages. These packages are delivered by community care providers in conjunction with the general practitioner and are commonly supplemented with family carer support. Numbers of packages providing high level care (Extended Aged Care at Home [EACH] and Extended Aged Care at Home in Dementia [EACHD] packages) increased by 25%, and 27% respectively from 2009 to 2010.<sup>6</sup> In June 2010, nationally, there were 40,134 clients receiving low level care packages (Community Aged Care Packages [CACPs]) and 7,546 receiving high care packages.<sup>6</sup>

**Figure 1: Implementing palliative care**



Given the advanced age and disabilities of package recipients, deaths of clients are not uncommon. From 2009 to 2010, 17% of CACPs, 33% of EACH, and 20% of EACHD separations occurred because of death.<sup>6</sup> A further 46% of CACPs, 46% of EACH packages, and 66% of EACHD packages

ended with a residential aged care placement.<sup>6</sup> Within residential aged care, the mean length of stay for permanent residents was 145 weeks, with 90% of separations occurring because of death, 25% of these within 6 months of admission.<sup>7</sup>

Overseas studies suggest that a diminishing number of people are dying at home and that this is especially true of older people.<sup>8,9</sup> Consistent with such findings, a recent Western Australian (data linkage) study showed that over 60% of a sample of approximately 800 community dwelling older people who died (in 2005/6) of conditions amenable to palliative care were in hospital on the last day of life.<sup>10</sup> Adopting a palliative approach can help support a wish to die at home by implementing plans to avoid unnecessary transfers due to foreseeable health care crises. However, provision of this approach requires consideration of diverse care needs and contexts.

Care needs of this cohort of older people exist because of (potentially multiple) health conditions with physical, mental, and/or cognitive impacts. Recently, in the Australian State of Victoria, co-morbidity, depression, and dementia were all identified as common in home care clients, with caregiver strain also prevalent.<sup>11</sup> Care contexts are similarly diverse. In 2009/10, for example:

- 15% of EACH and 19% of EACHD clients preferred to speak a language other than English;<sup>6</sup>
- 30% of EACH and 24% of EACHD recipients lived alone;<sup>6</sup> and
- approximately 10% of older EACH recipients were in outer regional, remote, or very remote areas.<sup>6</sup>

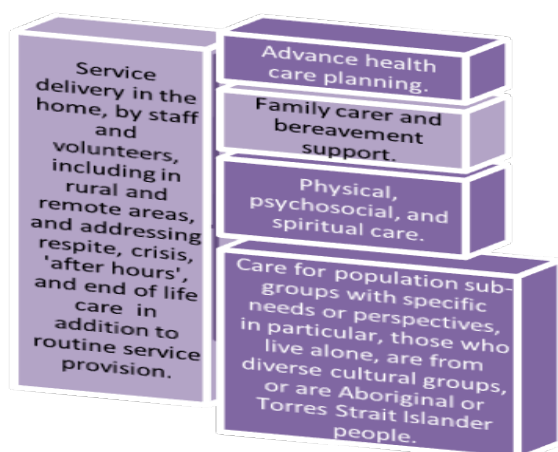
Determining how a palliative approach may be provided to each individual older person within the given care context therefore presents considerable challenges. Evidence and information to underpin service delivery is correspondingly critical. The *Guidelines for a Palliative Approach for Aged Care in the Community Setting*,<sup>12</sup> approved by the National Health and Medical Research Council, provide a suite of resources to inform practice.

#### *Development of the main guideline document*

The main guideline document was developed for use by general practitioners, nurses, therapists, social workers, pastoral care workers, and other professionals who are delivering or coordinating community aged care. The first step was an extensive national consultation process involving focus groups with 172 people from metropolitan, regional, rural, and remote areas. Participants included consumers, practitioners, educators, researchers, service managers, and support workers.<sup>12</sup> The project's reference group also provided extensive input. Areas designated as

appropriate for inclusion as a result of this consultative process are shown in Figure 2.

**Figure 2: Areas determined to be appropriate for inclusion<sup>12</sup>**



'Service delivery' and 'Family carer and bereavement support' were areas viewed as critical to delivery of a palliative approach in the community. Therefore, these areas were addressed with systematic reviews, which informed the development of evidence based guidelines. Questions to guide these reviews were developed from the consultative process and prioritised by the guideline development group; those addressed were:

1. Does the implementation of a post-acute transitional care program lead to improved physical and/or psychological health of the client and/or the family carer?
2. Does a model of care that includes 24 hour crisis care (access to 'after hours' medical, nursing, and/or pharmaceutical support) improve physical and/or psychological health in clients and/or family carers as compared with a model of care that does not include this crisis care?
3. Does a model of care that includes respite care improve physical and/or psychological health in clients and/or family carers as compared with a model of care that does not include this respite care?
4. Does education for family carers in disease-specific areas (i.e., dementia care, heart failure, chronic

obstructive pulmonary disease, cancer care, Parkinson's disease) improve family carer confidence; competence; physical, psychological, and spiritual health when compared with a lack of this education?

5. Does education for family carers in end-of-life care improve their experience of the death of their family member and their post bereavement health as compared with a lack of this education?

To answer these questions, a systematic search for evidence was carried out, with strict inclusion and exclusion criteria set.<sup>13</sup> The body of evidence addressing each question was then considered at a meeting of the guideline development group.<sup>13</sup>

Findings from this process are documented in two chapters, central to the document, that provide eight evidence based guidelines. These guidelines address post-acute transitional care, crisis care, and respite care delivery, as well as disease specific family carer education.

Needs of population sub-groups are addressed in discussion chapters considering:

- Aboriginal and Torres Strait Islander communities;
- those from diverse cultural and language groups;
- those living alone without nearby family support;
- those experiencing mental illness, acute stress disorder, post-traumatic stress disorder, or an intellectual disability;
- those experiencing motor neurone disease, Parkinson's disease, or dementia (contributed by specialists in these areas); and
- those who identify as gay, lesbian, bisexual, transsexual or intersex people.

Further literature reviews form the basis of chapters addressing advance health care planning, psychosocial care, and spiritual support.<sup>12</sup> Physical care is addressed in terms of symptom management, with descriptions of these symptoms and links to relevant existing guidelines.<sup>12</sup>

Refinements were made to the document based upon input received during a period of public comment advertised in the national press. Each individual comment was considered, and responded to, by the guideline development group.<sup>13</sup>

In the final document, good practice points, developed from literature reviews and expert opinion, are presented within each chapter and summarised at the start of the document. Needs specific to care delivery in rural and remote areas are addressed throughout. Links and references to many additional guidelines, tools, and resources are also included.



For example, the chapter on family carers provides references for family carer assessment tools; notes barriers to accessing support; explains recommended components of family support, including those applicable at the very end of life; and provides references/links to bereavement resources.

Figure 3 provides an example of one of the guidelines and extracts from a good practice point relevant to supporting end-of-life care in the home. This guidance can help to avoid unnecessary out of home transfers and facilitate implementation of a wish to die at home, when this is both feasible and desirable in the given situation.

**Figure 3: Sample guideline and extracts from good practice point**

*Guideline: Crisis care<sup>12</sup> (p.5, grading of recommendation explained in document)*

When implementing community-based health care services for older adults with specific or non-specific life-limiting illness, frailty, or extreme old age, access to crisis care should be included.

*Good Practice Point: Care at the End of Life (p.9)*

A formalised plan for end-of-life care will help make sure that the care is delivered in the best possible way. This plan needs to take account of any cultural preferences and should:

- make sure that advance care plans are documented, known, understood, and current;
- identify the needs of the family carer for support;
- document availability of staff or other support after hours;
- identify any equipment that might be needed and its availability, especially after hours;
- provide advice to the carer that the death is likely to occur soon (*more detail is supplied*);
- make sure the family knows what to do and whom to contact in the event of a change, a crisis, and when death occurs;
- provide a plan to support the family if it is likely that the person who dies will need to remain in the home for hours after the death (*more detail is supplied*);
- provide information about signs that death has occurred (those that are appropriate to the individual situation may be explained to family carers who ask for this information) (*more detail is supplied*).

*Development of the plain English booklets*

A plain English booklet was drafted from the main document to make the material more accessible to older

people and their family carers and to care workers. Four focus groups were held in metropolitan and rural areas to obtain feedback. The 37 participants included care coordinators and care workers, ‘home helps’, volunteer support workers, older people receiving care, and informal carers.<sup>13</sup> Participants provided written comments on the draft document and responded to the following questions:

1. What are your feelings about the document overall?
2. Would you use this document?
3. How do you feel about the appropriateness of the language used?
4. Please comment on the usefulness of the scenarios provided. How could these be improved?
5. What do you feel is the most useful section of the document? Why is it so useful?
6. What do you feel is the least useful section of the document? How could this be improved?
7. Is there anything requires changing in this document?
8. Do you have any further comments to make?

The reference group further contributed to this process. Alzheimer’s Australia, the Australian Government Department of Veterans’ Affairs, expert contributors to the main document, and a representative of the Respecting Patient Choices (advance care directive) program were also invited to comment.<sup>13</sup>

Responses resulted in the single booklet being split into two separate documents, one for care workers and the other for those receiving care and their family carers. Changes were also made to improve the clarity and usefulness of the booklets, which address care planning, physical and non-physical symptoms, spiritual issues, transfers to and from hospital, crisis care, family support, managing grief and bereavement, and end of life care.<sup>13</sup> Both booklets contain practical tips, case studies, and contacts for additional information; the one for care workers also provides information specific to the care of older people with Parkinson’s disease, dementia, or motor neurone disease.

*Obtaining and using the resources*

Contents of the main guideline document are useful for health care practitioners seeking information about:

- a palliative approach for older people living at home, its key tenets, and ways in which it may be implemented;
- family carer support; and
- implementing this approach in specific contexts.

The plain English booklets are tools that may be used when planning and providing a palliative approach. The care worker booklet is a useful training resource. The booklet for





older people and their family carers can support discussion and reflection as a preliminary step informing care plans; it also provides practical suggestions.

All the resources are available for downloading from CareSearch [www.caresearch.com.au](http://www.caresearch.com.au) (click on What is Palliative Care?>National Palliative Care Program>ComPAC). Hard copies of the main guideline and supporting booklets are also available from the Australian Government Department of Health and Ageing ([www.health.gov.au/palliativecare](http://www.health.gov.au/palliativecare) click on the Palliative Care Publications order form). Process documentation is available electronically via the CareSearch link.

## Conclusion

Increasingly, it is recognised that older people can be supported at home until they die, if this is their wish and that of their family carers. The new resources provide evidence based guidelines, good practice points, and a synthesis of the relevant literature; they also provide tools and links to additional resources. The resources are intended to facilitate a planned approach to home care that addresses quality of life and death as a priority in this client group. Therefore they are directed at those providing aged care within the community, including general practitioners. Support for family carers is addressed as a critical issue. At a time when hospitals and residential aged care facilities are under enormous pressure as our population ages, such a planned approach makes impeccable sense for the health system as a whole. The approach also makes sense for older people who wish to die in their own homes and their family carers, in that it helps avoid distress caused by unnecessary hospitalisation or residential placement, or by clinically futile interventions.

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## PEER REVIEW

Not commissioned. Externally peer reviewed.

## CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

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The Australian Government Department of Health and Ageing funded the *Guidelines for a Palliative Approach for Aged Care in the Community Setting: Best practice guidelines for the Australian context* and is supporting their distribution; facilitating electronic downloads and providing hard copies upon request. Plans also exist for extending education in a palliative approach into the community aged care sector.<sup>5</sup>

## ETHICS COMMITTEE APPROVAL

Edith Cowan University Human Research Ethics Committee, Reference 07-20 TOYE (1939).