



Dying at home: Preferences and the role of unpaid carers

A discussion paper on supporting carers for in-home, end-of-life care

May 2014

When someone has an illness which will lead to death and no effective treatment is available, palliative care involves managing the progression toward death and maintaining the best quality of life possible.

Palliative care aims to prevent and relieve suffering by early identification, assessment and treatment of pain and other problems.¹ There are no exact rules about when palliative care begins or ends. It generally begins when an incurable medical condition is diagnosed and, in terms of providing continuing support for carers, ends sometime following death. Palliative care addresses the physical, psychosocial and spiritual needs of patients and understands the role and the importance of carers in end-of-life-care.

It is widely recognised that most people prefer to die at home rather than in a clinical setting.² While health professionals understand people's preferences and aim to support patient choices, the majority of people die in admitted inpatient settings.³

Aside from patient preferences, another factor likely to contribute to the higher incidence of people dying at home is that the ageing of the population is likely to put increasing strain on the availability of inpatient care.

This paper looks at the role of the carer in meeting patient preferences for end-of-life care. It will discuss how carers can be enabled to better support patient preferences to die at home.

¹ World Health Organization. WHO definition of palliative care at: <http://www.who.int/cancer/palliative/definition/en/>

² Grande, G.E, Addington-Hall, J.M. et al 1998, *Place of death and access to home care services*, Soc Sc Med, 47:5, pp 565-579, in *PCA Submission to Senate Community Affairs Committee, Private Health Insurance Bill 2006*, p. 3.

³ Australian Institute of Health and Welfare 2012, *Australia's Health 2012*, p. 91.

The Context

- During 2009-10, 52% of all people who died in Australia died while admitted to hospital.⁴
- Patients with cancer comprise the majority of patients that use palliative care in Australia.⁵
- Palliative care is also available to people with life limiting conditions, which include dementia, Muscular Sclerosis, Parkinson's disease, Motor Neurone Disease, heart disease, stroke, and lung disease.
- At least 50% of all deaths in Australia each year are clinically expected because of advanced disease.⁶
- In their last year of life, Australians with advanced disease will average eight hospital admissions and incur a 60%-70% chance of dying in the hospital.⁷
- Most palliative care patients receive their care in the 'admitted patient setting' which refers to a hospice, a palliative care ward, or other hospital ward.
- The average length of hospital stay for palliative care hospitalisations in 2009 was 11.9 days, or about 4 times the average length of 3.1 days for all other hospitalisations.⁸

Dying at home

A person's home can provide familiarity, comfort, privacy and normal routines that admitted inpatient settings simply cannot provide.

We recognise that "home" will mean different things to different people. For many, a residential aged care setting is their home and will be the place where they prefer to die.

For those who can or would prefer to die in their own domestic environment being cared for by friends and family, the capacity of these carers to be well supported is vital.

Providing end-of-life care in the home is particularly intense for family and friend carers. While managing their own grief and the grief of others, carers will be providing high level physical and emotional support that a patient needs at the end-of-life. They will need to liaise

⁴ Ibid.

⁵ Mitchell, G.K., 2011, *Palliative Care in Australia*, The Oschsner Journal, Vol. 1, pp. 334-7.

⁶ Scott I., Mitchell G., Reymond E., Daly M., 2013, '*Difficult but necessary conversations - the case for advance care planning*', Medical Journal of Australia, 199 (10), pp. 662 – 666.

⁷ Ibid.

⁸ Australian Institute of Health and Welfare 2012, Australia's Health 2012, p. 449.

with a range of service providers, making clinical and other care decisions and making the necessary preparations for the time following the death.

It follows that if the carer is well supported throughout this experience, they will have more control over end-of-life care for the patient and greater satisfaction from fulfilling the patient's wish to die at home. And with greater numbers of carers supported to provide end-of-life care in the home, there will be less dependence on institutions and hospitals.

Barriers to dying at home

Not all patients will be able to die at home.

Many patients, carers and families will prefer a hospice or palliative care ward and they will be supported in that decision. There are also obviously cases where people do not have a carer at home and are unable to get formal care support to be able to die at home, even if this is their preference.

Palliative care services are committed to supporting carers, but there is potential for the health system to further support and encourage carers willing to provide end-of-life care at home.

In the UK, a study showed the main reasons for 52% of participants not achieving their preferred place of death were:

- * uncontrolled pain and complex symptoms
- * inability to guarantee 24-hour care in the community
- * delayed discharge from hospital; and
- * rapid deterioration and the concerns of relatives.⁹

Similarly, in Australia, survey results have shown that people did not die in their preferred place because of:

- * patient and carer preferences
- * rapid and unexpected deterioration in patient condition
- * certain types of terminal conditions that require a level of palliative care hospitals are best equipped to provide¹⁰
- * the limited availability of carers and other health-care services; and
- * an inability to manage at home.¹¹

⁹ Damanhuri, D., 2014. *What factors influence the terminally ill patient referred to the hospital specialist palliative care team in a NHS hospital, not achieving their preferred place of death? A critical evaluation.* BMJ Support Palliative care, 2014 March 4 Supp 1: A 54-55.

¹⁰ Ibid.

¹¹ Glare et al. 2003

Good communication: the basis for quality end-of-life care

Health and palliative care services, patients, carers and families working together improve the chances of meeting patient preferences in end-of-life care. The following principles underpin high quality, community-based and in-home palliative care that is inclusive of carers:

- * Improved access to and coordination of end-of-life-care
- * The engagement of carers and family in planning end-of-life care
- * Advance care planning and preparation of an advance care directive
- * Provision of education and supports to carers and family; and
- * Follow-up care with bereaved carers and family

Health professionals, services and support groups have a shared role in helping carers and families overcome barriers to patients dying at home. Health professionals can:

- * determine preferences for end-of-life-care and place of death
- * assist people to complete an advance care directive
- * assess inpatient condition and co-ordinate timely discharge home in accordance with patient preference
- * communicate with the carers and encourage carers in their capacity to manage the dying process in their home, and
- * arrange multidisciplinary supports for the patient, carer and family.

Against this background, the role of the primary care system and GPs are vital in supporting patients who wish to die at home.¹² There is evidence that there are barriers to greater involvement of the primary health system and GPs in palliative care, but there is also evidence to suggest that 'more proactive involvement of GPs can enable more terminally ill people to die at home'.¹³

¹² Mitchell, G.K., 2011, *Palliative Care in Australia*, The Oschsner Journal, Vol. 1, pp. 334-7.

¹³ Jin-Oh Rhee, J., Zwar, N., Vaghokar, S., et al, 2008, *Attitudes and barriers to involvement in Palliative care by Australian urban general practitioners*, Journal of Palliative Medicine, Vol. 11: no. 7, pp. 980-985.

Carers and admitted patient settings

If patients decide they do not wish to die at home, or if other circumstances prevent this, the caring role does not end in an inpatient setting. Family-centred palliative care is as relevant for inpatient settings as it is for home care.¹⁴ Every effort should be made by health professionals and acute care services to move dying patients to a private, quieter room, and support carers and family to remain with the patient.

In inpatient settings the carer will continue to:

- * provide personal care, for up to 24 hours a day
- * provide emotional support
- * be an advocate for the patient, including substitute decision making and ensuring the patient's preferences are met; and
- * be the communicator for the patient.

There are important initiatives being undertaken to ensure high quality end-of-life care in acute hospitals, with standards currently being developed by the Australian Commission on Safety and Quality in Health Care. These and other initiatives should contribute to improved end-of-life care outcomes for dying patients, their carers and families.

¹⁴ Hudson, P. 2013, 'Home based support for palliative care families: challenges and recommendations', MJA, Vol.179, pp: S35-S37.

Discussion

Carers and advance care planning

Good communication and collaboration involving health and palliative care professionals, the patient, carer and family assists the process of advance care planning. This process enables people to document their personal decisions and preferences for health care, including end-of-life care, while they have the capacity to do so. Advance care planning can prevent and resolve certain issues and dilemmas encountered in end-of-life care, such as whether people would want aggressive medical treatments and interventions, or would prefer not to have their life unnecessarily prolonged. Research shows that:

“Having end-of-life discussions with physicians is associated with pursuing less aggressive medical care and having earlier referrals to hospices. Furthermore.... more aggressive care was associated with worse patient quality of life, as well as poorer caregiver bereavement adjustment.”¹⁵

Advance care planning prompts people to have the difficult discussions about death. Carers that are included in advance care planning, develop the knowledge and confidence to become the patient’s substitute decision-maker. Carers come to understand patient preferences for medical treatments as well as their preferred place of death, spiritual supports and funeral arrangements.

Other benefits for carers include:

- * improved opportunity for communication and collaboration with health professionals
- * reassurance that the patient’s decisions are safeguarded in the event they lose the capacity to make decisions
- * reduced likelihood that a patient will receive aggressive or futile health care at the end-of-life
- * a sense of control from the ability to assess the “congruence between expressed patient wishes and the actual care received”.¹⁶

¹⁵ World Health Organisation 2008, *WHO definition of Palliative Care*, 2008, retrieved <http://www.who.int/cancer/palliative/definition/en/>

¹⁶ Scott I., Mitchell G., Reymond E., Daly M., 2013, ‘*Difficult but necessary conversations - the case for advance care planning*’, *Medical Journal of Australia*, 199 (10), pp. 662 – 666.

Until advance care planning becomes “embedded in routine clinical practice [and] the public’s consciousness”, health professionals may not see that responsibility for initiating, coordinating and documenting discussions about advance care planning is an important part of their role.^{17 18} Therefore, advance care directives won’t always guarantee access to palliative care, or safeguard a person’s preferences.¹⁹ For example, a person admitted to a hospital Emergency Ward, with limited capacity and without their carer, is vulnerable to having clinical decisions decided by staff. The presence of the carer while discussing patient care is a helpful safeguard of patient preferences.

There are many initiatives underway across Australia to promote the use and uptake of advance care planning and directives. Alzheimer’s Australia has the excellent START2TALK website that educates and assists patients, health professionals, carers and family complete the process of advance care planning.²⁰

Improved engagement and communication with carers

People with a preference to die at home will require that their carer and home are sufficiently supported and equipped to provide end-of-life care.²¹ End-of-life symptoms can be challenging to manage and distressing to observe. The type and severity of these symptoms, and the carer’s and family’s ability to cope, will underpin the coordination of end-of-life care. Carers and family need a high level of support prior to and throughout challenging care situations, in order for the patient to remain in the home environment.²²

Difficult caring situations can be trigger points for decisions to transfer the patient to an inpatient setting. This in turn increases the likelihood that death will occur in the admitted patient setting. Unfortunately, it can also mean that patients receive care that they do not want or need at the end-of-life. Health and palliative care services will need to manage and facilitate the continuation of end-of-life care in the home. Assessment of the current and potential risks for admission, and formulating a plan of action, may help prevent admission to an inpatient setting when a crisis or other intense situation occurs.

¹⁷ Ibid.

¹⁸ Ibid.

¹⁹ Ibid, p. 662.

²⁰ Alzheimers Australia, START2TALK website at: <https://www.start2talk.org.au/>

²¹ Stajduhar K. & Cohen R. ‘Family caregiving in the home’ in Hudson P., & Payne S. (eds) Family Carers in Palliative Care, 2009, Oxford University Press, UK p. 149-150.

²² ACT Government Health 2013, *Palliative Care Services Plan 2013-2017*, p. 7.

While death is an individual experience, much of what carers and family can expect and need to know can be communicated through regular and on-going education.²³ Important information that carers need include the:

- * patient's prognosis, symptoms and clinical care
- * necessity or otherwise of medications and other interventions
- * reasons for clinical decisions
- * available supports and referrals; and
- * actions to take in a crisis.

Good communication is a prerequisite for engaging with carers. Most of the complaints that are received by the Aged Care Complaints Scheme in regard to palliative care settings concern communication problems between staff, carers and family. The reasons for this includes the inability of patients to communicate for themselves and their dependence on family and friends to communicate for them, the difficult emotional time for carers and family, and the grief and distress often experienced by carers and family at this time.²⁴

The following suggestions were found to be applicable to palliative care in a residential aged care setting, but are equally applicable to other inpatient settings. Health professionals can engage better with carers by:

- * undertaking professional development training in communication so they are able to support carers and family
- * listening to the carer
- * supporting carers to remain with the patient; and
- * understanding and acknowledging grief, distress and the need for emotional support.²⁵

Cultural considerations in end-of-life-care

The cultural diversity of Australia means that the interdisciplinary approach to providing end-of-life care must use specific engagement and communication strategies to support people from Culturally and Linguistically Diverse (CALD) groups and Aboriginal and Torres Strait

²³ Bee, P.E., Barnes, P., Luker, KA. 2009, *A systematic review of informal caregivers' needs in providing home-based end-of-life-care to people with cancer*. Journal of Clinical Nursing, May 2009; Vol. 10 1379-93.

²⁴ Department of Social Services 2014, *DSS industry Feedback Alert, Effective communication in Palliative Care*. Commonwealth of Australia.

²⁵ Ibid.

Islander cultures. This requires health care professionals to be 'culturally aware, culturally sensitive and culturally competent'.²⁶

"Impedance of optimal management of Indigenous cases (cancer care) largely revolves around lack of cultural understanding and culturally appropriate techniques which can give rise to problems such as ineffective communication."²⁷

Across different cultural groups, there will be a range of preferences, practices and traditions surrounding death and they will contribute to people choosing to die at home or not. There are a number of factors that have been identified as influencing the involvement of Aboriginal and Torres Strait Islander people in palliative care. Knowledge of the following issues are important for primary care services and GPs in particular as they are a central component in medical services in Indigenous communities.²⁸

- * recognising cultural diversity among Aboriginal people
- * acknowledging and valuing Aboriginal and Torres Strait Islander identity
- * family and kinship ties
- * choice of place of death
- * culturally appropriate consent
- * ceremonies and practice
- * treatment environment
- * models of care provision
- * funerals
- * post death requirements; and
- * loss and grief support²⁹

There are many resources for health professionals to use; training packages such as the Indigenous culture training programs offered by the RACGP and the National Indigenous Cancer Network's education about cancer from an Indigenous perspective are two

²⁶ Clark, K., Phillips, J. 2010 'End-of-life care: The importance of culture and ethnicity', Australian Family Physician, April 2010, Vol. 39 (4) 177-256. Retrieved from: <http://www.racgp.org.au/afp/2010/april/end-of-life-care-%E2%80%93-the-importance-of-culture-and-ethnicity>.

²⁷ Saunders, V., Elston, J., & Gennat, H. 2002, in Tillmann, A. 2013, *Cancer in General Practice*, Australian Quarterly, Vol. 84, (4), Oct-Dec 2013, pp. 20-5.

²⁸ Australian Indigenous HealthInfoNet (2009) Review of cancer among Indigenous peoples, in Tillmann, A. 2013, *Cancer in General Practice*, Australian Quarterly, Vol. 84, (4), Oct-Dec 2013, pp. 20-5.

²⁹ The National Palliative Care Program 2004, *Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander people* retrieved from: <http://www.caresearch.com.au/Caresearch/Portals/0/Documents/WhatisPalliativeCare/NationalProgram/IndigenousPCproject/PracticePrinciples.pdf>

examples.³⁰ The National Indigenous Palliative Care Needs Study has also provided evidence about the needs of Indigenous people in end-of-life-care.³¹

After death support – regardless of where the patient dies

The palliative approach includes bereavement care. Following the death, the carer and family will require follow-up bereavement care. Carers need support to make the necessary adjustments to their own changed circumstances, including loss of the caring role, financial challenges and making plans for their future.

Conclusion:

In-home and community based palliative care is going to be increasingly on the agenda as the population of Australia ages and there is continuing emphasis on the importance of patient preferences in end-of life care. The role of carers in providing end-of-life care in the home is crucial. Carers require more support, education and engagement with health professionals, services and supports if they are to meet patient preferences for place of death. Improved quality of planning, communication and education for carers for end-of-life care may assist more people to die at home.

³⁰ Tillmann, A. 2013, *Cancer in General Practice*, Australian Quarterly, Vol. 84, (4), Oct-Dec 2013, pp. 20-5.

³¹ <http://www.caresearch.com.au/caresearch/tabid/86/Default.aspx>

Recommendations to enable carers to meet patient preferences for place of death:

1. *Excellent access to palliative care services and coordination of care to support patient and carer preferences*
 - 1.1 Early identification of patients approaching the end of their life.
 - 1.2 Timely and appropriate referrals between services.
 - 1.3 Acute hospitals to develop policies and procedures for working with carers, palliative care services, GPs, residential aged care facilities, and others, 'to optimise collaboration and coordination of end of life care as patients move in and out of hospital'.³²
 - 1.4 Improved communication between acute services and primary care services as patients transfer from inpatient settings to their home.
 - 1.5 Flexibility in end-of-life care in hospitals including; mobile hospital palliative care teams, and quiet, family-friendly ward settings for palliative care if discharge home is not possible.³³

2. *Engaging carers and family in the planning of end-of-life care in the home*
 - 2.1 Individualised strategies to support the end-of-life care for the person dying and their carer, taking into account that not every carer will be able to provide end-of-life care at home.³⁴
 - 2.2 Inclusion of carers in discussions, clinical decisions and planning of end-of-life care.

3. *Advance Care Planning and preparation of an Advance Care Directive*
 - 3.1 Hospital staff to access advance care directives of people upon admission to an inpatient setting, and identify and contact a person's carer and/or substitute decision-maker before making treatment decisions.³⁵
 - 3.2 Health professionals to increasingly take 'responsibility for initiating, coordinating and documenting discussions about advance care planning'.
 - 3.3 Train doctors and nurses to talk to patients while they have the capacity to make decisions themselves.³⁶

³² 2014, ACSQHC, National consensus statement: Essential Elements for safe and high-Quality End-of-Life Care in Acute Hospitals, p. 1.

³³ Gomes G., Calanzani N., Higginson IJ. 2011, *Local preferences and place of death in regions within England 2010*, Cicely Saunders Institute, p. 21.

³⁴ Northern Sydney, Central Coast, NSW Health 2010, *A Guidebook...Supporting end-of-life care at home*, p. 21.

³⁵ Ibid, p. 10.

3.4 Refer patients, carers, and families to appropriate resources to support the use of advance care directives.

4. *Education of carers and family and ensuring they have support networks*

4.1 Crisis management planning for unexpected events to alleviate carer uncertainty and stress.

4.2 Carers to be encouraged to develop their network to share caring with other family members and friends. Health professionals and services to assess the carers support network and offer respite care and other support if necessary.³⁷

4.3 Recognition and acknowledgement that in end-of-life care the carer's home becomes a 'public space'. Understand that the carer will feel frustrated at the loss of privacy and 'sense of invasion'. Develop strategies to alleviate this, i.e. respite care.³⁸

4.4 Health professionals and services to become culturally aware and culturally sensitive in order to better engage with culturally diverse groups.

5. *Follow-up care with bereaved carers and family*

5.1 Recognise the transitions and adjustments that carers are making throughout their bereavement period.

5.2 Health services and professionals need to promote the health and wellbeing of carers, encouraging regular health checks for carers, and ensuring that carers have timely access to counselling services, including during bereavement.^{39 40}

³⁶ Tomazin, F. 2014, *Death with Dignity Reform*, The Age, March 16, 2014.

³⁷ Nth Sydney, Central Coast, NSW Health 2010, *Carers Guidebook... Supporting end-of-life care at home*, p. 7.

³⁸ Carers Victoria 'Unrecognised grief and loss', p. 22.

³⁹ Ibid.

⁴⁰ Palliative Care Australia, *Carers and end-of-life position statement*, retrieved from: [http://www.palliativecare.org.au/Portals/46/PCA%20Carers%20and%20End%20of%20Life%20Position%20State ment.pdf](http://www.palliativecare.org.au/Portals/46/PCA%20Carers%20and%20End%20of%20Life%20Position%20Statement.pdf)