



An ethical framework for integrating palliative care principles into the management of advanced chronic or terminal conditions

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Section I: Introduction

Aims of the framework

This framework aims to facilitate best ethical practice for those people who are receiving palliative care for an advanced chronic or terminal¹ condition in the last twelve months or so of their lives. The framework has been designed to guide the deliberations of individual health professionals as they consider the ethical dimensions of the care they deliver at this stage of a patient's journey through a chronic condition and / or a terminal illness, including cancer.

The framework is intended to complement other professional practice guidelines and standards as well as relevant legislation in State and Territory jurisdictions. For example, *Guidelines for a Palliative Approach in Residential Aged Care*², *National Palliative Care Strategy 2010*³, position statements issued by professional organisations such as the Australian Medical Association and Royal College of Nursing, Australia, and other professional practice guidelines such as codes of ethics and of conduct.

Scope of the framework

This framework document has been prepared with a companion guide for patients, families and carers entitled *Living well with an advanced or chronic condition: How ethics helps. A guide for patients, family and carers*⁴. The documents are intended to be used together although they can also be read separately.

Both this framework and the companion guide identify and describe ethical principles and values of relevance in the final twelve months or so of a person's life, namely: clinical integrity; respect for persons; justice; and beneficence.

In this framework the four ethical principles and values are discussed individually and then questions are posed that are suggested by reflecting on each of the ethical principles and values in the context of palliative care. Recognising that each patient-health professional encounter is unique, the framework does not seek to provide a resolution to each situation addressed by the questions. Where appropriate, web link resources are identified to assist individuals as they determine best ethical practice in each circumstance.

While the focus of this framework (and its companion guide) is on adults of all ages, not only the elderly, the ethical principles and values will also be relevant to younger people with advanced chronic or terminal conditions who are also in need of palliative care.

1 The word 'terminal' has been shown to be preferred by consumers. For details, refer to Palliative Care Victoria Communication Strategy June 2006. This strategy is a report of research commissioned by Department of Human Services Victoria, to improve awareness and understanding of palliative care in the general community. The research was carried out by OpenMind Research Group, March 2006.

2 National Health and Medical Research Council. (2006). *Guidelines for a Palliative Approach in Residential Aged Care 2006*. NHMRC, Canberra. Retrieved 6 May 2011 from <http://www.nhmrc.gov.au/publications/synopses/ac12to14syn.htm>

3 Australian Government Department of Health and Ageing. (2010). *The National Palliative Care Strategy – Supporting Australians to Live Well at the End of Life, 2010*. Retrieved 4 May 2011, from <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-strategy.htm>

4 <http://www.nhmrc.gov.au/guidelines/publications/rec31>



Who is this framework for?

This ethical framework is addressed to *health professionals*. Its intention is to highlight the ethical reasons for the integration of palliative care into the management of advanced chronic or terminal conditions, including cancer.

Palliative care should not be confined to 'end of life' care. Research is showing increasingly that when palliative care is introduced in conjunction with active treatment of a life-limiting condition, both life expectancy and quality of life can be improved⁵. There is also evidence that palliative care input for such patients decreases inappropriate hospitalisations and the associated use of high cost acute care⁶. The contribution of palliative care, therefore, is relevant not only when a person's symptoms are not being addressed adequately by their other treatments, but also for optimal patient management and efficient use of resources.

Although the palliative management of a patient and their symptoms is the responsibility of all relevant health professionals and lay carers (to the best of their ability), the expertise of health practitioners who have specialised in palliative care should be sought as soon as the person's symptoms indicate the need. Hence some experts suggest, as a guide, that if a health professional would not be surprised if a particular patient were to die in the next year or so, then the expertise of palliative care practitioners should be sought in order to manage any symptoms which interfere with quality of life, e.g. pain, breathlessness, confusion and distress. The timely provision of palliative care well before the final months of a person's life, gives individuals and their families an opportunity to plan for a good remaining period of life, as well as to prepare for death⁷.

The context for the framework

The provision of health care is multi faceted and people's needs are often complex. With the many advances in health care has come a corresponding danger of over-specialisation. In addition, the complexity of the health care system sometimes leads to fragmented services and care.

In this context, the relationships between a person and their health professionals are at the heart of medicine, nursing and allied health care. These relationships should never be thought of in isolation. Consequently, there is a need for greater integration of services and for effective collaboration and communication between health professionals. Integration of this kind enhances continuity of care for a person with advanced chronic or terminal conditions (including cancer) and facilitates the informed involvement of their carers, thus contributing to an improved quality of life.

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- 5 See for example, Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D. (2010). Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer *N Engl J Med.* 363:733-742. Daisy J.A. Janssen, Martijn A. Spruit, Nicole H. Uszko-Lencer, Jos M.G.A. Schols, Emiel F.M. Wouters. (2011). Symptoms, Comorbidities, and Health Care in Advanced Chronic Obstructive Pulmonary Disease or Chronic Heart Failure – *Journal Of Palliative Medicine* 14:6. Haines, Ian E. (2011). Managing patients with advanced cancer: the benefits of early referral for palliative care *MJA.* 194:3, 7 February 2011.
- 6 Haines, Ian E. (2011). Managing patients with advanced cancer: the benefits of early referral for palliative care *MJA.* 194:3, 7 February 2011.
- 7 Murray, S. A., Boyd, K., Sheikh, A. (2005). 'Palliative care in chronic illness'. *BMJ* 350, 611-612. Retrieved 31 March 2009 (p612) from <http://www.bmj.com/cgi/reprint/330/7492/611>



Accordingly, the framework explains the ethical reasons why *palliative care* treatments (which may or may not involve specialist services) should be integrated into the management of people with advanced chronic or terminal conditions, and why collaboration and communication between health professionals is so essential to effective and timely care in such circumstances.

The framework holds that clear ethical concepts and terminology help to ensure that the process of decision making is transparent and that its basis and validity is readily understood.

The application of the ethical principles and values in the framework should be subject to recognising and encompassing the cultural or religious values and traditions of the individuals concerned. For example, for Aboriginal and Torres Strait Islander Peoples the importance of return to country may influence which treatment options will be adopted⁸.

Development of the framework

The ethical principles and values described in the framework and the companion guide have been developed by an expert sub-group of the Australian Health Ethics Committee (AHEC) of National Health and Medical Research Council. The Sub-group included members with expertise in palliative care, medicine and nursing, religion, bioethics and consumer issues (listed in Appendix 1). AHEC as a whole has expertise in law, philosophy, medicine, public health and social science research, concerns specific to Aboriginal and Torres Strait Islander Peoples and issues for people with disability.

In developing the framework and its companion guidance document the expert AHEC sub-group sought input from a diverse range of stakeholders via a targeted consultation process (September – October 2008), and a public consultation process (October 2009 – January 2010). Submissions to both consultation processes were received from individuals as well as organisations representing consumers, health care professionals, various faith based organisations, advocacy groups and State and Territory Departments of Health (however called).

8 Australian Government Department of Health and Ageing. (2004). Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander Peoples: Resource Kit (Supports training within mainstream health services for the provision of palliative care to Aboriginal and Torres Strait Islander Peoples), and Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander Peoples: Practice Principles (Provides strategies that have been developed specifically to support palliative care services and personnel to meet the cultural needs of Aboriginal and Torres Strait Islander Peoples, their families and communities). Retrieved 6 May 2011 from <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-indig-resource.htm>



Section 2: Ethical Values and Principles associated with Palliative Care

What is Palliative Care?

Palliative care has been defined as:

“an approach that improves the quality of life of patients and their families facing the problems 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.”⁹

Moreover:

“Like few other areas in health care, palliative care is both a phase of care and a specialty service.”¹⁰

Australian governments have adopted the World Health Organisation’s definition of palliative care, as noted in the *National Palliative Care Strategy 2010* (the Strategy)¹¹.

The Strategy guides palliative care initiatives and services. The Strategy is the policy document that the Australian Government and State and Territory governments use to guide palliative care policy development and service delivery across Australia.

The Strategy has four goal areas:

Awareness and Understanding

- To significantly improve the appreciation of dying and death as a normal part of the life continuum.
- To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to palliative care services.

Appropriateness and Effectiveness

- Appropriate and effective palliative care is available to all Australians based on need.

Leadership and Governance

- To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches.

Capacity and Capability

- To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care.

9 World Health Organisation. (2004). Better Palliative Care for Older People. Prepared by Davies, E. & Higginson, I., J. World Health Organisation. Retrieved February 2009 from <http://www.euro.who.int/document/e82933.pdf>

10 Draft National Palliative Care Strategy 2010, p 4. Retrieved August 2010 from <http://npcsu.comuniogroup.com/>

11 Australian Government Department of Health and Ageing. (2010). The National Palliative Care Strategy – Supporting Australians to Live Well at the End of Life, 2010. Retrieved 4 May 2011 from <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-strategy.htm>



This framework is consistent with the goals articulated in the Strategy. The framework will contribute to the awareness and understanding of the ethical aspects associated with dying and death as a normal part of the life continuum, not only for older Australians, but for anyone at any age with an advanced chronic or terminal condition who would benefit from palliative care.

Accordingly, the framework has been developed to demonstrate that there is an *ethical* reason for ensuring that people have adequate understanding of where palliative measures fit into their care and an *ethical* reason why health professionals should collaborate with each other more effectively in order to ensure that people receive the best available care and treatment.

These ethical reasons depend on values, priorities and principles that underpin good clinical practice. The *National Statement on Ethical Conduct in Human Research (2007)*, along with other NHMRC guidelines such as *Ethical Guidelines For The Care Of People In Post-Coma Unresponsiveness (Vegetative State) Or A Minimally Responsive State (2008)*¹², identify key ethical principles and values that are well recognised in the Australian community. Adapted to the care of people with advanced chronic or terminal conditions, the Sub-group has identified these values as:

1. **Clinical integrity**
2. **Respect for persons**
3. **Justice**
4. **Beneficence.**

¹² NHMRC. (2007). National Statement on Ethical Conduct in Human Research. Retrieved 13 October 2010 from <http://www.nhmrc.gov.au/publications/synopses/e72syn.htm>

NHMRC (2008). Ethical Guidelines for the Care of People in Post-Coma Unresponsiveness (Vegetative State) or a Minimally Responsive State 2008. Retrieved 13 October 2010 from, http://www.nhmrc.gov.au/publications/synopses/e81_82syn.htm

The following diagram represents the relationship of these ethical principles and values to each other



The ethical principles and values can be described as follows:

Clinical integrity refers to the importance of respecting all of a person's values, needs and wishes in the context of health care. It thus requires continuity and integration of the best available care and treatment in order to bring genuine **benefit** to the person with an advanced chronic or terminal condition, and in a way that is **just** to all concerned¹³.

Respect for persons requires that people's wishes be respected and that they be helped to participate in decisions about their treatment or care, to the extent that they are informed, willing and able¹⁴.

Justice requires that those who are ill and all other people involved in their care – families, carers, and even the wider community – are treated fairly and that limited resources are used responsibly and wisely¹⁵.

Beneficence requires that the person's changing needs and preferences about care and treatment options and sites of care are recognised, regularly reviewed and acted upon, so that the person may live as comfortably as possible in this final phase of their advanced chronic or terminal condition, with their inalienable human dignity always respected¹⁶.

¹³ Clinical integrity in the care of patients parallels the value of research merit and integrity in the conduct of research, as explained in the National Statement on Ethical Conduct in Human Research (Section one). In the clinical care context of this framework the value of clinical integrity should guide professionals to reflect, not only on their own professional practice, but also on the relationship between their contribution to a person's care and the necessary contributions of other professionals. NHMRC. (2007). National Statement on Ethical Conduct in Human Research. Retrieved 13 October 2010 from <http://www.nhmrc.gov.au/publications/synopses/e72syn.htm>

¹⁴ NHMRC. (2007). National Statement on Ethical Conduct in Human Research. Retrieved 13 October 2010 from <http://www.nhmrc.gov.au/publications/synopses/e72syn.htm>.

¹⁵ Beauchamp, T.L., & Childress, J. F. 2009. 6th ed. Principles of biomedical ethics. New York, Oxford University Press.

¹⁶ Beauchamp, T.L., & Childress, J. F. 2009. 6th ed. Principles of biomedical ethics. New York, Oxford University Press.



Section 3: Applying the ethical principles and values

I. CLINICAL INTEGRITY

A Introduction

The overriding goal of health care, as of any medical or other intervention, is to help people sustain the life and health that are essential to their total well being, including their ability to make their own decisions and to live independently. The value of clinical integrity implies that health care interventions are unethical when they are not beneficial to an individual, because they do not, for example, save life or cure or slow the progress of life limiting conditions or relieve distressing symptoms.

Clinical integrity has two aspects. With respect to clinical practice, it requires health professionals to recognise when the expertise of other professionals should be sought. In the case of people with advanced chronic or terminal conditions, specialist palliative care will often be needed to keep people as free of pain and other suffering as is possible so that they can live well until they die.

Secondly, with respect to personal integrity, it concerns both integrity in one's personal character and consistency in one's actions. In caring for people making the transition to end of life care, health professionals need to develop the skills required to facilitate the person's journey through the maze of clinical and healthcare supports. Above all, clear communication with both the person and their other health professionals regarding the disease process, its likely trajectory and anticipated future needs is vital, as is the need for some health professionals to lead the collaboration about a person's care.

B Key issues

The key ethical issues in relation to clinical integrity concern:

- ensuring the continuing and integrated care of a person as their health care needs change in the course of an advanced chronic or terminal condition
- health professionals understanding the extent and the limits of their own expertise and acknowledging the essential contribution of other professionals and
- the development and maintenance of good lines of communication.

Inadequate collaboration and / or poor communication among the health care professionals and the patient and carers may result in a lack of care planning and divergent decisions about the care required and, thus, confusion for the patient and their family and carers.

In addition, when it becomes clear that treatments for an advanced chronic or terminal condition are no longer effective and that life may be coming to an end (even though death is not yet imminent), then the introduction of a general palliative approach to care should occur in a way that does not exclude other care and treatments.

Early consultation with the person and their family as well as the health professionals involved is critical, so that the transition to palliative care and other forms of care can be gradual. Clinical integrity demands that people should not normally find themselves abruptly transferred to palliative care in the last days of life (unless deterioration is sudden and unexpected).



Should a person raise the question of euthanasia, or speak of ‘wanting to die’, it is always important to explore the person’s reasons for raising the issue at this time: whether the patient’s symptoms are being well managed, how serious the request is and for how long held, and whether the request is known to and supported by family and carers. In this situation, people are often seeking reassurance that they will not be abandoned by their carers and health professionals.

C Application of the ethical value of clinical integrity

Clinical integrity in the context of advanced chronic or terminal conditions requires

that:

1. People are given the best available continuing and integrated treatment and care as their health care needs change due to advanced chronic or terminal conditions
2. Responsible health professionals undertake a specific review of a person’s treatment, care options and wishes if they believe death would not be a surprise within the next twelve months
3. People are referred in timely and transparent ways to the most appropriate health professionals
4. Health professionals communicate and collaborate with each other in a timely and regular way
5. Review by multidisciplinary health teams is available when needed, if such teams exist.



D Some key questions for health professionals to ask themselves

1. Would I be surprised if my patient died in the next twelve months or so?
2. Is there a need to introduce a specialist palliative approach to care alongside symptomatic treatment of the advanced chronic or terminal condition?
3. Have I had a conversation with the person regarding their wishes as the end of their life approaches, even if death is not yet imminent?
4. Do I have sufficient information regarding the supports this person has from their family carers and others? How will communication be maintained with these people? Do I / we have the person's approval to discuss the care plans with their family or carer?
5. Have I consulted / communicated with relevant colleagues about the care of my patient?
6. Have I kept the person's medical practitioners and other relevant health professionals up to date on their condition and their care?
7. Have I clearly documented all discussions and information relating to care, treatment and communication with other professionals provided to the person and/or their advocate / representative?
8. Have I provided for the person's emotional, physical, spiritual, social and cultural well-being? If professionals are not available for one-on-one time with the person, has consideration been given to alternatives such as a friend or regular volunteer visitor?
9. What resources do I have for discussions about euthanasia if this is raised by the person or families and carers? Am I able to have an open and honest discussion canvassing all of the relevant issues: for them and for me? Am I familiar with relevant State and Territory legislation and guidelines?
10. Are there others who can assist me in supporting this person's autonomy and respecting their human dignity? How do I go about enlisting their support?
11. Are there regular reviews of the person's care at interdisciplinary team meetings? Has a clinical care plan been developed for the person (not to be confused with the person's advanced care directive) including plans to address possible functional decline with appropriate medications and support?
12. Have workflow duties been adjusted to provide a daily time slot for staff to sit with the person (if they so desire)?
13. How will I deal with a person's stated wishes (or an advance directive) when I reasonably consider that those wishes are not in the person's best interests or not in keeping with best clinical practice?
14. Has spiritual and / or cultural support been made available to the person? (e.g. hospital / health service chaplains, volunteer visitors)?
15. Does the person have reasonable access to all information and options relating to their care, changed treatment, management and access to other health professionals or health care settings?
16. Does the person /advocate / representative fully comprehend the effects that withdrawal or cessation of curative treatment will cause?
17. Have I discussed the development of an advance care directive in the event that the person does not have one?



2. RESPECT FOR PERSONS

A Introduction

A fundamental value for all health professionals is respect for persons irrespective of their background, condition or culture. Respect for persons is the basis for the traditional professional health care maxims of non-maleficence (*Primum non nocere* – ‘above all, do no harm’) – and beneficence (do what is good for a person and in their best interests). The requirement of always acting in the best interests of the person requires a focus on *the person* whose beneficence is at stake.

The decision about what is in a person’s ‘best interests’ is best made by the person concerned or by their representative (or both collaboratively). The role of health professionals is to act as a partner in health care by maintaining open and frequent communication and assisting the person or their representative to fully understand the information and its implications for them as individuals.

Decisions about what care is offered must respect the person’s beliefs and values, and the things he or she holds to be most important, even if these differ from the family or the health care professional’s views. Decisions also need to respect cultural or religious beliefs, and the specific needs of groups such as Aboriginal and Torres Strait Islander Peoples, people from culturally and linguistically diverse communities, and those with a disability.

Decisions must also be carefully documented in order to record the person’s wishes and to prevent the need to repeat the decision making process; such repetition can itself create unnecessary burdens. Decisions should be regularly reviewed in the light of changes in a person’s condition or situation and that review should always have as its aim the best interests of the person.

B Key issues

The key ethical issues in relation to respect for people in this last phase of their lives concern:

- Encouraging people to be involved in their health care decisions (to the extent that they want to and are able to be), to plan for their future needs and to appoint a representative if desired
- Providing accurate and timely information about a person’s advanced chronic or terminal condition and the available care options, with timely and transparent referrals to the most appropriate health care professionals
- A primary focus on the best interests of the person, rather than the interests of others involved, including family members, health professionals or carers. (*Note:* Impact on carers and others are considered below under the value of justice.)
- Careful discussion to enable the person’s views to become clear.

Health professionals should remember that people are more likely to rely on the judgement of their appointed representatives, family members and health professionals if they are confident that their wishes have been understood and respected. Risk information, non-curative treatment options and alternatives to that treatment should be explained in clear simple language, if necessary by obtaining the services of a qualified interpreter.



Good care of a person will normally involve collaboration between different health professionals. Informed consent should be obtained for information to be shared with others in the health care team. The provision of factual information about care options, either to the person concerned or their representative, should be separated from personal opinion about what the health professional or team thinks should occur. Health professionals should seek to ensure that they have a good understanding of the person's situation and circumstances, and should ensure a person is never coerced into particular treatment or care decisions by others.

C Application of the ethical principle of respect for persons

Respect for persons in the context of advanced chronic or terminal conditions requires that:

1. Health professionals seek to discover the extent to which people are willing and able to be informed about their condition and prognosis
2. People are given accurate and timely information that enables them to understand the prognosis for their advanced chronic or terminal condition and the available care and treatment options
3. People's wishes about their care and options are sought and respected
4. People are encouraged and given appropriate support to adapt to the changes in their condition, to plan for their future needs, and to appoint a representative if they so wish
5. A person's right to refuse additional treatment/s that they believe are having a negative impact upon their comfort and quality of life is recognised and respected
6. When people are unable to make health care decisions, their previously expressed wishes (or advance care directives) are identified and respected to the extent that they are still applicable and / or appropriate (*Note:* See last pages of this document for web links to advance care directives and other relevant resources)
7. The cultural and spiritual beliefs and practices of the person and their family are acknowledged and respected at all times.

D Some key questions for health professionals to ask themselves

1. How do I achieve individual person-centred care that respects the emotional, physical, spiritual and cultural needs of the person?
2. Does the person have access to all relevant information and options relating to their care, changed treatment options and access to other specialist health professionals or health care settings?
3. Should the person be encouraged to develop an advance care plan at this time?
4. Has the person expressed their wishes clearly (regarding all aspects and / or limitations of care)?
5. Have I appropriately documented my discussions with the person and, in instances where an Advance Care Directive exists, recorded its existence?
6. Is it appropriate to initiate a family case conference to discuss the advance care plan?
7. If an advance care plan has been prepared, in particular an Advance Care Directive, has it been revisited throughout the person's time in transition?
8. How can the person's autonomy be preserved even if their physical independence has been reduced or lost?
9. Does the person have (or require) an advocate or representative to act on their behalf? How do I know that?

10. Does the person have a reasonable opportunity to alter or change their wishes? Has this been expressed clearly to the person?
11. Have I kept the person's medical practitioners and other relevant health professionals up-to-date on their condition / care?
12. How will I deal with wishes stated in an advance care directive that I consider are not in the person's best interests or in accordance with best clinical practice?
13. Is specialised palliative care available for the person after time in general palliative care?
14. Do I need to seek any clarification (e.g. from a Guardianship Act) in assessing a person's autonomy and determining their best interests in a case where the person is without capacity (e.g. a child, person with cognitive disability, etc.)?



3. JUSTICE

A Introduction

The value of justice embraces many aspects of health care provision.

First, there is the requirement of justice towards the person concerned – for example, by avoiding both under-treatment and over-treatment, by preventing harm due to the use of multiple drugs, and by ensuring that people receive treatment in the setting most appropriate to their current needs.

Second, health professionals work within the context of a health system in which resources are finite. Because of this constraint, justice to all means that decisions to provide a particular treatment need to involve consideration of the potential benefit for the person as well as the legitimate needs of others. In the final year or so of life, treatments will normally aim less at cure, and more at relieving current symptoms, reducing suffering, and maintaining a quality of life that enables the person to achieve their goals and wishes.

Third, justice also requires that the legitimate and reasonable needs of families and carers be considered so that they are not unnecessarily overburdened or overwhelmed.

In short, justice in the delivery of health care involves respect for and fair benefit to all concerned. The dignity of persons must be both morally and legally respected, so that justice is done and is seen to be done.

B Key issues

The key ethical issues in relation to justice in the care of people with advanced chronic or terminal conditions concern:

- Decisions about where a person should be cared for – e.g. at home, in an acute care facility, an aged care facility or in a hospice
- Decisions about the level of care that should be provided and about who can best provide it
- Consideration of the wishes and needs of family and carers
- Decisions about equitable access to scarce or expensive resources (e.g. medications and equipment).

At times, people only need access to a particular service in an acute care facility, e.g. a specialised test. In this instance, that person should be able to access specific services without being subject to the full clinical pathways normally provided by the acute facility. Good communication, in the form of referral notes for example, assists in preventing unnecessary investigations and / or treatment.

Those who wish to receive care at home need to have equitable access to the supports required, as well as being clearly informed about what can or cannot be achieved in this setting. Justice towards family and carers requires that their needs be considered when selecting the site of care. Justice in these matters requires good communication between health professionals, and clear pathways for management of the person that do not impose unnecessary interventions or burdens upon them.

Resource allocation problems are exacerbated in rural and remote areas where access to specialist health services, palliative care expertise, and specialist nursing, allied health and medical personnel, is limited. Likewise, people from population groups with particular needs can also be disadvantaged by resource issues. Where it is available, and it could be obtained relatively easily, it is never fair or just to deny reasonable access to specialist palliative care and treatment. For example, sufficient resources to provide appropriate care for Aboriginal and Torres Strait Islander Peoples who live in isolated communities and those from culturally and linguistically diverse communities, may be lacking. It also needs to be acknowledged that the inequitable distribution of resources can place unfair burdens on those who live and work in rural and remote areas.

Another potential injustice may arise when culturally appropriate practices during the later stage of life are not known or appreciated by the health care team. In these situations, it may be beneficial to consult with specialist advisors (or others) from the person's community to maximise choices and enhance understanding. Although the provision of these resources does have a cost, it is potentially inequitable to deny access simply because of resource allocation difficulties.

Justice also bears upon the need for good communication between health professionals and the people they serve. In fairness to all, communication should be open and respectful and decisions documented and reviewed regularly. Although persons and their families may be dependent upon others, they should, as a matter of justice, always be respected as persons and involved in decision making to the extent that they are willing and able.

The wishes of the person, the legal protections that support this, and the proper roles of the family and / or carer must also be respected. Ignorance of relevant moral and legal issues on the part of health professionals may lead to injustice against people and their families.

C Application of the ethical principle of justice towards people

Justice towards people, their families and carers in the context of advanced chronic or terminal conditions requires that:

1. Health professionals avoid any kind of actual or perceived unjust discrimination against people, e.g. on account of their age, race, spiritual beliefs or disadvantaged situation
2. Health care resources are used responsibly, wisely and fairly
3. The needs of family and other carers are taken into account when changes to a person's management plan are being considered. With the person's consent, family and other carers (as applicable) are included as part of the care management team
4. People's preferences about where they are cared for (e.g. in their own homes) are sought and implemented, if this is practicable, safe and fair to others
5. People and / or their family members should be involved in decisions about transfer to other sites of care (e.g. to a palliative care unit / hospice, nursing home or an acute care hospital)
6. People with limited access to health care, e.g. in rural and remote areas, should still have reasonable access to essential specialist and palliative care expertise
7. The relevant legal protections and government resources should be made available to people and their carers (*Note:* See last pages of this document for web links).



D Some key questions for health professionals to ask themselves

1. What Government or other financial supports are available to my patient?
2. Should this patient continue to be treated in the current setting (e.g. a tertiary hospital)?
3. How can I ensure that my patient will be treated appropriately if I send them for tests or management at a tertiary hospital? How can I ensure that professionals in other settings, like a tertiary facility, sufficiently understand the circumstances the patient will be returning to? What communication and referral strategies will assist this understanding?
4. What responsibilities for the care of this person may fairly be asked of unpaid volunteer or family carers?
5. What kind of resource allocation is needed to improve or maintain the quality of care for those in transition to palliative care?
6. What training, education and support services ought to be provided to other carers to deliver such care?
7. What support services or community groups are available to provide further assistance to the person in addition to medical, nursing and allied health care?
8. Are there other people with advanced chronic or terminal conditions under my care who may benefit from earlier discussion or awareness of the issues surrounding transitional care before it is actually required by them?
9. If resources are limited, am I managing these in a way that is most beneficial for the person? What services are currently being utilised by the person and family and will a change in status (e.g. to palliative care) affect access to these services?
10. Is there a need to make decisions required by legislation, for example, under a Guardianship Act?
11. Are there advocacy measures I should take to help improve care for patients and their carers at this stage of their lives?



4. BENEFICENCE TO THE PERSON

A Introduction

Health care decisions are most likely to benefit a person when they:

- are based on sound clinical judgments;
- respect the person, family and carers; and
- acknowledge the constraints of the just provision of health care services.

As previous sections have explained, benefit to any person depends on a wide range of factors including the integration of care and treatment options, the fulfilment of a person's own preferences, the relief of distressing symptoms, open lines of communication, collaboration among health professionals, appropriate sites of care, and so on. Because many factors bear upon benefit to the person, decisions about what will be most beneficial for a particular individual in any given situation may be complex.

In the case of people with advanced chronic or terminal conditions, who are entering the last year or so of their lives, the benefits of care and treatment will generally move from cure or maintenance to the relief of symptoms and improving quality of life. What was previously beneficial may cease to be beneficial. As the goals of care and treatment and the condition of the person change, other people will normally need to be involved in decisions about what would now be beneficial. Health professionals need to recognise when the relevance and benefits of their own specialist contribution is coming to an end.

B Key Issues

The key ethical issues in relation to determining benefits for people in the last twelve months or so of their lives concern:

- Understanding what is in a person's best interests, given their overall needs
- Judging whether a care modality, treatment option or intervention may be judged to be futile or overly burdensome for a particular person
- Using and interpreting advance care plans or directives
- Dealing with disagreements / conflict.

Understanding what is in a person's best interests

Concern for a person's 'best interests' acknowledges whose interests should be paramount, and how those interests are rightly determined. The person requiring care is usually the best one to judge which of the legally available and professionally appropriate care or treatment options will be most beneficial for themselves. If someone is not able to express their wishes, then others who know them well – for example, family and carers – will usually be best able to say what the person would want in the circumstances.

Assessment of what is in a person's best interests in relation to a care decision must take into account:

- a. the person's values, beliefs and critical interests
- b. the person's previously expressed wishes, to the extent that they can be ascertained, and whether the present circumstances correspond to the situation that the person imagined when expressing or recording those wishes



- c. the wishes of a nearest relative or other family member/s, if it can be confidently assumed that the family's wishes are aligned with the person's best interests
- d. the benefits and burdens of care and treatment options and the consequences to the person if the care or treatment is not carried out, having regard to the level of confidence about prognosis at the time a decision is made
- e. the relative merits of any other care or treatment options and
- f. the nature and degree of the risks associated with any changes to care and treatment options.

Judging whether a specific care modality, treatment option or intervention may be futile or overly burdensome for a particular person

While there is an ordinary level of care for health and life that professionals are legally obliged to provide, it is always necessary to consider whether a specific care modality, treatment option or intervention may be judged to be futile or overly burdensome for a particular person – either by the person themselves, by their legally appointed representative or guardian, or by health professionals.

Benefits of care and treatment may include:

- a. slowing down the progress of the chronic condition
- b. sustaining the person's life
- c. reducing disability and improving health and
- d. relieving the person's distress or discomfort.

A treatment or care modality may be described as futile if it brings no benefit at all the patient¹⁷. For example, artificial nutrition and hydration (ANH) is futile if it fails to sustain the person or bring comfort.

Treatments that bring some benefit may, nonetheless, be quite burdensome. **Burdens** of care and treatment include distress and suffering to the person. Decisions about care and treatment may also need to take into account the impact on the family and community.

Care and treatments may be judged to be **overly burdensome** when the burden of that care or treatment for the person is disproportionate to the likely benefits. Whether a particular care or treatment is overly burdensome is determined by assessing and balancing the risky, intrusive, destructive, exhausting, painful or repugnant nature of the care or treatment against its benefits or chance of success.

Such decisions are informed by the person's and the family's particular circumstances, their experience of the advanced chronic or terminal condition and its remedies and their culture, beliefs and preferences. These decisions may also need to take into account the burden or cost of the care and treatment and the availability of resources for the family and / or community.

For example, circumstances may develop in which the delivery of ANH becomes overly burdensome and may be withdrawn. While any treatment that prolongs a person's life may be beneficial in principle, it may cease to be beneficial for a particular person if it merely prolongs the dying process or is overly burdensome and undermines the person's quality of life. Determination that a treatment is overly burdensome relies on expert knowledge of the person's diagnosis, co-morbidities and the likely impact of proposed care and treatment in this setting.

¹⁷For discussion of the various meanings of 'futile', and for the reasons for understanding it in this way, see: NHMRC. (2008). Ethical Guidelines for the Care of People in Post-Coma Unresponsiveness (Vegetative State) or a Minimally Responsive State. p35. Retrieved 13 October 2010 from, http://www.nhmrc.gov.au/publications/synopses/e81_82syn.htm



Using and interpreting advance care plans or directives

People can express their future health care wishes in several ways. However, the legal status of these expressions may vary depending on the jurisdiction; therefore, legal advice relevant to the jurisdiction may need to be sought.

When a person becomes incompetent he or she is no longer able to respond to the current circumstances. There is, however, always a moral responsibility to provide reasonable health care in these circumstances. Because the progression of pathology in advanced chronic or terminal conditions can be individualistic and uncertain, an incompetent person's earlier wishes and values should guide, rather than direct, the specific treatment and care decisions to be made in the actual circumstances that later arise. Although the earlier expression provides evidence of the person's past wishes, the health professional must still make responsible decisions in the actual circumstances with the guidance of the person's legally appointed representative.

Health professionals should assess the applicability of the care plan in the actual circumstances and judge whether any requests made can be met in keeping with responsible medical practice, individual professional conscience and the values of any health care institution concerned with the person's care. Usually, collaborative discussion with the person's representative leads to agreement about a revised future care plan.

There may sometimes be an unresolved difference, especially if the person or the person's representative insists on elements in the health care plan that require the health professional or institution to act unethically, or illegally. In such cases, the health professional or institution may have to decline to provide a specific treatment, provided that ordinary care is continued, and no one is endangered by this decision.

Dealing with disagreements

Disagreements can arise between the health professionals caring for a person, between health professionals and the person, between the person and their carers or between all groups. There may be different views about what is in a person's best interests, about where the person can best be cared for, and about the focus of changing care and treatment options at a particular time.

Honest communication between all parties in a spirit of good will and concern for the person will usually allow consensus or a working agreement to emerge.

Practical ways to prevent or resolve disagreements include:

- Maintaining regular communication between professionals, and with people and their representatives and carers
- Allowing as much time as is required for repeated discussions
- Promoting time limited active treatment options
- Seeking a second opinion
- Requesting review at an appropriate legal tribunal
- Obtaining the assistance of a patient advocate or liaison officer or other mediation services¹⁸.

¹⁸Please refer to the Web-link section of this Framework for further information and guidance, for example <http://www.caresearch.com.au/caresearch/FindingEvidence/PalliativeCarePubMedSearches/tabid/322/Default.aspx>



C Application of the ethical principle of beneficence

Beneficence to the person in the context of advanced chronic or terminal conditions requires that:

1. The (changing) goals of care are clearly identified and evaluated in the light of the person's overall needs and preferences
2. Palliative care principles are introduced into a person's care as early as appropriate
3. When it is relevant, the inevitability of death and its likely timing are discussed with the person concerned (or the culturally appropriate person), and their family, in a way that respects cultural and spiritual values
4. Decisions to withdraw or withhold futile or overly burdensome treatments are informed wherever possible by the known or presumed wishes of the person or their family / representative
5. Any disagreements about treatment and care decisions are acknowledged honestly, and worked through in a cooperative manner.

D Some key questions for health professionals to ask themselves

1. Should the primary focus of treatment now change from cure to relief of symptoms? How will this be determined?
2. Would I be surprised if this person died in the next twelve months or so?
3. Am I offering realistic options for care and treatment? Am I explaining the likely outcomes of care in a way this person and their family can understand?
4. How can I integrate a palliative care approach into the care of this person? Am I sufficiently aware of the palliative and any condition-specific needs of this person?
5. Should specialist palliative care advice be sought?
6. Has the care and treatment become futile or overly burdensome in the view of the person?
7. Is this person being cared for in the most appropriate setting to meet their expressed wishes and needs?
8. Has this person understood the information and explanations I have given? Would translator or interpreter services be helpful?
9. Am I satisfied that the person's choices have been made voluntarily (i.e. under no duress) and that they are being respected?
10. Have I involved the person and their carers / family in reviewing their care plans at key times during their care? Who is the best person to lead discussions about a change in care focus?
11. Have I fully explained and offered all possible appropriate care and treatment options and resources to this person and to those close to them and/or to those who care for them?
12. Am I taking enough time to hear what the person and their family consider to be a burdensome intervention or an unacceptable outcome?



Conclusion

This framework document has drawn attention to the ethical reasons why health professionals should work together collaboratively to ensure continuity of care for people with advanced chronic or terminal conditions as they enter the final phase of their lives and as their situations and care and treatment options change.

Respect for people requires helping them to engage with decision making to the extent that they are able to and wish to be involved. Justice to all concerned requires the concerns of family and carers to be taken into account. Beneficence to the person will often require advance care planning, the use of end of life clinical pathways, and specific decisions to limit, withhold or withdraw treatments that have become futile or overly burdensome. In striving to realise these values, good ethics and good clinical practice go hand in hand.

GLOSSARY

The Glossary has been adapted and developed drawing on the definitions provided in both the *National Palliative Care Strategy*¹⁹ and Palliative Care Australia's *Glossary of Terms*²⁰ as well as other sources as indicated.

- Advance care planning** “The process of preparing for likely scenarios near the end of life that usually includes assessment of, and discussion about, a person’s understanding of their medical condition and prognosis, values, preferences and personal and family resources. Advance care planning support patients in communicating their wishes about their end of life”²¹.
- Beneficence** In the context of advanced chronic or terminal condition, the value of beneficence requires that the person’s changing needs and preferences about care and treatment options and sites of care are recognised, regularly reviewed and acted upon, so that the person may live as comfortably as possible in this final phase of their life, with their inalienable human dignity always respected²².
- Best Interests** Recognition of a person’s ‘best interests’ acknowledges whose interests should be paramount when decisions need to be made, and how those interests are rightly determined. The person requiring care is usually the best one to judge which of the legally available and professionally appropriate care or treatment options will be most beneficial for themselves.
- Chronic condition** “A biological or physical condition where the natural evolution of the condition can significantly impact on a person’s overall quality of life, including an irreversible inability to perform basic physical and social functions. Serious and persistent chronic conditions are multidimensional, interdependent, complex and ongoing. Chronic and complex conditions are characterised by persistent and recurring health consequences lasting for an extended period of time”²³.
- Clinical Integrity** The value of clinical integrity affirms the importance of ensuring that patients receive all the various forms of treatment and care that they need in their particular circumstances. It thus requires collaboration between health professionals in order to ensure continuity and integration of the best available care and treatment so as to bring genuine benefit to the person with an advanced chronic or terminal condition, and in a way that is just to all concerned.
- End-of-life** “The international definition is ‘last two years of life’. By comparison the term used in the Northern Territory is ‘the final five days’. The average time people are on end of life care is 37 hours”²⁴. This framework concerns the last twelve months or so of a person’s life.

19 Australian Government Department of Health and Ageing. (2010). Supporting Australians to Live Well at the End of Life: National Palliative Care Strategy–2010.

20 Palliative Care Australia. (2008). Palliative and End-of-life Care: Glossary of Terms, 1st ed.

21 Australian Government Department of Health and Ageing. (2010). Supporting Australians to Live Well at the End of Life: National Palliative Care Strategy–2010. p 19.

22 Beauchamp, T.L., & Childress, J.F. 2009. 6th ed. Principles of biomedical ethics. New York, Oxford University Press.

23 Australian Government Department of Health and Ageing. (2010) Supporting Australians to Live Well at the End of Life: National Palliative Care Strategy–2010. p 19. Palliative Care Australia. (2008) Palliative and End-of-life Care: Glossary of Terms, 1st ed. p 5.

24 Australian Government Department of Health and Ageing. (2010). Supporting Australians to Live Well at the End of Life: National Palliative Care Strategy–2010. p19.



Futile	<p>The term ‘futile’ is used in various ways by health professionals. This document follows recent NHMRC usage:</p> <p>“Treatment is futile only if it produces no benefit to the patient (i.e. does not slow down the progress of disease, sustain the patient’s life, reduce disability and improve health, or relieve the patient’s distress or discomfort). Treatment ought not to be continued or initiated if it is futile”²⁵.</p>
General palliative care	<p>General palliative care is the responsibility of all health care professionals (and carers) to the extent of their ability to address a person’s symptoms or other distress.</p>
Justice	<p>Justice is the most wide ranging of all ethical values. In the context of this framework, it requires that those who are ill and all other people involved in their care – families, carers, and even the wider community – are treated fairly and that limited resources are used responsibly and wisely²⁶.</p>
Overly burdensome	<p>Care and treatments may be judged to be overly burdensome when the burden of that care or treatment for the person is disproportionate to the likely benefits. Whether a particular care or treatment is overly burdensome is determined by assessing and balancing the risky, intrusive, destructive, exhausting, painful or repugnant nature of the care or treatment against its benefits or chance of success.</p>
Quality of life	<p>“A term used with respect to assessing the outcome of interventions. It may be used in a formal way, engaging methods of scoring patient disability, discomfort and preferences.”²⁷</p>
Respect for persons	<p>Respect is the most fundamental value that should govern people’s relationships with one another. In the context of advanced chronic and terminal conditions it requires that people’s wishes be respected, and that they be helped to participate in decisions about their treatment or care, to the extent that they are informed, willing and able²⁸.</p>
Specialist palliative care	<p>“A specialist palliative care provider is a medical, nursing or allied health professional recognised as a palliative care specialist by an accrediting body or who substantively works in a specialist palliative care service if an accrediting body is not available”²⁹.</p>

25 NHMRC. (2008). Ethical Guidelines for the Care of People in Post-Coma Unresponsiveness (Vegetative State) or a Minimally Responsive State 2008. Canberra, ACT: NHMRC. p49.

26 Beauchamp, T.L., & Childress, J.F. 2009. 6th ed. Principles of biomedical ethics. New York, Oxford University Press.

27 NHMRC. (2008). Ethical Guidelines for the Care of People in Post-Coma Unresponsiveness (Vegetative State) or a Minimally Responsive State. Canberra, ACT: NHMRC. p50.

28 NHMRC. (2007). National Statement on Ethical Conduct in Human Research. Canberra, ACT: NHMRC.

29 Palliative Care Australia. (2008). Palliative and End-of-life Care: Glossary of Terms, 1st ed. p14.



Web links for Health Professionals

These links and resources have been provided to assist individual health professionals to access further information and advice in their deliberations about the ethical aspects of the care they are providing. The resources are not exhaustive, neither do they address every issue that may arise. Readers are encouraged to seek further assistance from appropriate resources if they decide that they need them in their particular circumstance/s.

Whilst National Health and Medical Research Council has taken every care to provide accurate and up to date information, readers are advised to confirm resources and web-links.

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Further information

National Health and Medical Research Council
T: 1300 064 672 02 or (02) 6217 9000
E: nhmrc@nhmrc.gov.au
www.nhmrc.gov.au



Appendix I

Role of AHEC

The statutory functions of the Australian Health Ethics Committee (AHEC) includes providing advice, or preparing guidelines, about ethical issues in health. The *National Health and Medical Research Council Act 1992* stipulates the diverse composition of AHEC and the necessity for public consultation in the development of guidelines. AHEC therefore understands that it is the will of the Parliament that AHEC seeks to prepare advice and guidelines that reflect and to some extent define the values of the Australian community.

Membership of the sub-group

Membership: 2009 - 2011

Name	Category
Rev Dr Gerald Gleeson	Member, Australian Health Ethics Committee and Chair of the Working Group
Professor Ian Olver AM	Member, Australian Health Ethics Committee
Professor Margaret O'Connor AM	Member, Australian Health Ethics Committee
Mr John Stubbs	Member, Australian Health Ethics Committee
Professor Merrilyn Walton	Member, Australian Health Ethics Committee

Membership: 2008 - 2009

Name	Category
Rev Dr Gerald Gleeson	Member, Australian Health Ethics Committee and Chair of the Working Group
Professor Colin Thomson	Chair, Australian Health Ethics Committee
Associate Professor Terry Dunbar	Member, Australian Health Ethics Committee
Professor Margaret O'Connor AM	Member, Australian Health Ethics Committee



Appendix 2

Process report

In developing and issuing guidance documents National Health and Medical Research Council (NHMRC) and its Principal Committees are obliged under the *National Health and Medical Research Council Act 1992* (Section 13 and 14A) to release draft guidance for public consultation.

In 2008, a sub-group of the Australian Health Ethics Committee (AHEC) developed an issues paper on the ethical issues associated with the end of life. The paper was circulated to 25 organisations and individuals for targeted consultation with 15 submissions received in response. The submissions were analysed by a sub-group of AHEC as it developed a second Issues Paper.

The second Issues Paper was released for public consultation over December 2009 – January 2010. A total of 41 submissions were received from a range of stakeholders. The submissions were considered by the AHEC sub-group as it prepared the final guidance documents.

The documents were presented to AHEC at the 25-26 May 2011 meeting. On AHEC's recommendation, the documents were forwarded to NHMRC's Council in April 2011 and again in June 2011, where they were endorsed.

NHMRC's Chief Executive Officer formally issued the two documents in August 2011.

