



Living Well With an Advanced Chronic or Terminal Condition: How Ethics Helps

A guide for patients, family and carers

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Introduction

Patients and their carers will sometimes realise that due to advanced chronic or terminal illness the final phase of life is approaching. National Health and Medical Research Council (NHMRC) wishes to emphasise that providing appropriate palliative care and treatment at this time is in keeping with the most important ethical values and principles in health care and with the most recent clinical evidence.

Every person affected by advanced chronic or terminal conditions, should receive good palliative care and treatment. It is important that all of the people involved in decisions around palliative care can understand the core principles and share the information that is needed to make the best possible decisions.

This guide explains the key ethical principles relevant to palliative care and identifies some questions to be explored by those involved (whether patients, their own doctors or nurses or a specialist service) and at any stage in the management of the condition (and particularly towards the end of life).

There are also some links to more information listed at the end of this brochure.

NHMRC understands that most people want to be involved in their own palliative care.

We have prepared questions and suggestions in a way that the patient may be able to use.

However, these questions can also be asked by family members, advocates, representatives or carers for the patient.

What is Palliative care?

Palliative care focuses on relieving symptoms such as pain or distress to promote well being, and may be required for many months before a person dies. A patient may need some palliative care while they are still being treated for their (underlying) condition or illness.

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.¹

The Ethical Principles

The ethical principles that promote good treatment include: clinical integrity, respect for persons, justice and benefit to the person. These principles guide health professionals in doing what is best for patients, their families and their carers. NHMRC has prepared information for health professionals involved in palliative care in *An ethical framework for integrating palliative care principles into the management of advanced chronic or terminal conditions*².

1 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>

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>

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



Clinical Integrity

Clinical integrity refers to care for the whole person, and so requires that palliative care expertise be sought as early as appropriate in order to ensure that patients are kept free of pain and other suffering, so they can live as well as possible in the time they have remaining.

Patients with an advanced chronic or terminal condition can expect that:

- as their health needs change, they will be given the best continuing and integrated care and treatment (including care by multidisciplinary teams if they are available)
- health professionals will review care and treatment options regularly and discuss them with the patient, their family and their carers
- they will be referred for palliative care in a timely way and according to their needs
- they will be able to discuss the most appropriate place to receive the care they need, given their family and other circumstances.

Some key questions for people to ask themselves to promote clinical integrity:

1. Is this the right treatment for this stage of my illness or condition?
2. Are my health care needs changing?
3. Has the likely course of the condition been explained to me by the doctor or a member of the health care team?
4. What changes in current circumstances are likely to occur because of changes in my health care e.g. changes in living arrangements?
5. How will changes in my condition and / or treatment affect other people?
6. Would I like to have another health professional review my situation?
7. Has sufficient information been provided to allow me to make the right decision about my future care or treatment?
8. Has my doctor or a member of the health care team provided my advocate or representative with sufficient information for them to make the right decision about my future care or treatment?
9. Is overall care being well-coordinated if a range of services is involved?
10. Do I know *who* is coordinating my care and treatment?
11. Where would I most like to be cared for at this time?
12. Has information been provided about all the implications of stopping a current treatment to me? What impact would this have upon me, my family or carers?



Respect for Persons

The patient is the best person to make decisions about their care, in keeping with their beliefs and values. Patients need to know that their values and beliefs will be respected even when they differ from those of their family or of health workers.

Patients with an advanced chronic or terminal condition can expect that:

- health professionals and others who care for them will find out from the patient how much the patient wants to know about the condition
- they will be given accurate and timely information so they can understand their condition, and the choices about care and treatment that are available to them
- their carers will find out and respect their decisions (directly or from the patients' chosen representative) about care and treatment in planning for the future
- their right to refuse additional treatments (which they or their chosen representative believe are negatively affecting the function, comfort and quality of life) is recognised and respected
- when they are unable to make decisions about their health care, previously expressed wishes will be identified and respected
- their cultural and spiritual beliefs and practices will be acknowledged and respected at all times.

Some key questions for people to ask themselves to ensure respect for persons are:

1. Have my wishes for future care been discussed with my family, friends and carers?
2. How can I know that my wishes have been, or will be, respected even if I become more dependent on others?
3. Do I need or wish to appoint a representative to speak on my behalf if I become unable to express my wishes?
4. Does my advocate or representative clearly understand my wishes (which may differ from their own opinions)?
5. Does an advocate or representative have the emotional, social, spiritual or cultural resources suitable for this role?
6. Do I understand the difference between an advance care directive (my directive) and a clinical care plan (as set out by health professionals for my care and treatment)?
7. Do I need or wish to make an advance care directive?
8. Do my wishes or advance care directives clearly state the care and / or treatment that I want or do not want?
9. What aspects of my quality of life matter most to me at this time?
10. Do my family, advocate or representatives accept the choices I have made? If they do not, do I understand why, and is there anything I can do to help them accept my wishes?
11. How and when can I begin to talk about my eventual dying with my family (or carers) in a way that is culturally appropriate for me and for them?
12. What do I, and / or my family, want in these circumstances?

Question for family and carers:

1. As family members, how will we go about planning to support our family member at this time in their life?



Justice

Justice in health care means taking into account the needs of all concerned – primarily the patient's needs, but also the needs of family members, carers and others involved with the patient at this time.

Patients with an advanced chronic or terminal condition can expect that:

- health professionals will avoid any kind of actual or perceived unjust discrimination against them, e.g. on account of their age, race, gender, sexual preference, spiritual beliefs or disadvantaged situation
- health care resources will be used responsibly, wisely and fairly
- their preferences about where they want to be cared for (e.g. in their own home) will be sought and implemented – if this is practicable, safe and fair to the patient and others
- the needs of family and other carers will be taken into account when changes to their management plan are being considered. With the patient's consent, family and other carers will be included as part of the care management team
- they (or their family or representative) will be involved in decisions about transfer to other sites of care (e.g. to nursing homes, to an acute care hospital or to a hospice)
- they will have reasonable access to essential specialist and palliative care expertise, e.g. by means of telemedicine, even if they have limited access to health care
- the relevant legal protections and government resources should be made available to them and to their family carers.

Some key questions for people to ask themselves to ensure justice in health care:

1. Do I think that the demands of my care are becoming a burden to others and how do I feel about that?
2. How can I discuss this with my family / carers so that we can 'talk it through' and reach a good result (e.g. that they care for me and continue with their own lives) for everyone's benefit?
3. Where would I most like to be cared for at this time? Would this be fair to others?
4. How can I encourage my family, advocate or representative to care for themselves and to continue with their own lives, while caring for me?
5. Where can my family, advocate or representative find references and resources to assist in their role in caring for me or making decisions on my behalf?
6. Am I satisfied with the level of service I am receiving from the health care organisation and do I know how to pass on my views to that organisation?
7. What support services are available for my advocate or representative?
8. How will my family prepare to support me and what resources will they need to do that?

Questions for family and carers:

1. What educational and training resources are available to me to assist me in providing high quality care?
2. Do I know what I am entitled to in relation to Government financial support as a carer? If not, how do I go about obtaining access to that support?



Benefit to the Person

In the context of advanced chronic or terminal conditions, achieving genuine benefit for the patient depends on recognising their changing needs. In palliative care, treatment is directed at managing symptoms so the patient is as pain free and as comfortable as possible.

In that context, overly burdensome treatments of the underlying condition are ones whose negative effects outweigh any minor benefits they may offer. Treatments that are, or would be, overly burdensome should not be commenced or continued.

For healthcare decisions to be of most benefit, patients should expect that:

- any changes in treatment, made as their condition changes, are clearly identified and evaluated in the light of their overall needs and preferences
- relevant treatment options, with the likely risks and benefits for the stage of disease, are presented to them in a way that they can understand
- palliative care is integrated into their care as early as is appropriate
- they can discuss the inevitability of death and an estimation of when it might occur, with a culturally appropriate person and / or their family in a way that respects their cultural and spiritual preferences
- decisions to withdraw or withhold futile or overly burdensome treatments are informed, wherever possible, by their known or presumed wishes or the views of their family or representative
- any disagreements between them and their healthcare team about care and treatment options are acknowledged honestly and worked through in a cooperative manner
- they can be represented by a patient advocate or a mediator and / or always seek a second medical opinion
- they can express their future healthcare wishes by writing them down or using a written advance care plan, discussing them with relatives or friends or appointing a representative to express their wishes if they are too ill to do so.

NHMRC recommends that any patient considering a written advance care plan seek legal advice in the State or Territory for that plan.

Some key questions for people to ask themselves to ensure that their treatment and care is truly beneficial:

1. Do I understand the clinical goals and the side-effects of the care and treatment I am receiving or will receive?
2. Am I getting enough out of this care and treatment to ensure good quality of life at this stage of my condition?
3. How will my current care and treatment affect my later condition? Will I be worse off in the long run?
4. What would make a treatment overly burdensome for me?
5. How will I know when to limit or withdraw a particular treatment?
6. Am I communicating my concerns to my carer, advocate, representative or medical professional?
7. If there is disagreement, what resources are there to assist me (and if relevant, my carer) in resolving them?



8. How can I ensure that those I choose are providing my care at this really significant time in my life?
9. How do I ensure that support and care is offered to my family and carers both before and after my death?

Questions for Family and Carers:

1. Am I the best person now to be providing care for this person? If I am not, where should I go for assistance?
2. Do I have sufficient resources to provide the care now required, e.g. lifting machines, and if not, how do I go about getting them?
3. Am I caring for my own needs so I can continue to provide the level of care the person concerned needs?
4. What resources are there to help me with this and how do I go about getting them?
5. How do I sort out what are the best interests of the person from the interests of family and others such as volunteers?
6. Do I have any further questions, even after the person has died, that I would like to ask the health care team?
7. Have I received adequate information about grief and bereavement counselling?



Conclusion

People with advanced chronic or terminal conditions often have changing health care needs that will require collaboration between different health professionals, and access to palliative care in particular.

This is in keeping with the fundamental ethical principles and values of clinical integrity, respect for persons, justice and benefit to the patient which help to ensure that health professionals always focus on what is best for you as a person.

If you have any questions about your care or treatment, feel free to raise them with your health professionals, family or carers at any time so that you can be supported at this time in your life.



GLOSSARY

The Glossary has been adapted and developed drawing on the definitions provided in both the *National Palliative Care Strategy*³ and Palliative Care Australia's *Glossary of Terms*⁴ 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”⁵.
- Beneficence** In the context of an 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 respected⁶.
- 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”⁷.
- 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”⁸. This guidance document concerns the last twelve months or so of a person’s life.

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

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

5 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.

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

7 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.

8 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.



Futile	The term 'futile' is used in various ways by health professionals. This guidance document follows recent NHMRC usage: "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" ⁹ .
General palliative care	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.
Justice	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 wisely ¹⁰ .
Overly burdensome	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.
Quality of life	"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." ¹¹
Respect for persons	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 able ¹² .
Specialist palliative care	"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" ¹³ .

9 NHMRC (2008). Ethical Guidelines for the Care of People in Post-Coma Unresponsiveness (Vegetative State) or a Minimally Responsive State. NHMRC, Canberra. p 49.

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

11 NHMRC. (2008). Ethical Guidelines for the Care of People in Post-Coma Unresponsiveness (Vegetative State) or a Minimally Responsive State. Canberra, ACT:NHMRC. p 50.

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

13 Palliative Care Australia. (2008). Palliative and End-of-life Care: Glossary of Terms, 1st ed. p 14.



Websites and resources for consumers

These websites and resources have been provided to assist individual patients, their family and carers, 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 websites..

Aged Care Australia. Retrieved 10 May 2011 from <http://www.agedcareaustralia.gov.au/>

Australian Government Directory of Services for Older people. Retrieved 10 May 2011 from [http://www.health.gov.au/internet/main/publishing.nsf/Content/AB724C0DE3D26BAFCA2576A9007B98CC/\\$File/AGDOS2011.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/AB724C0DE3D26BAFCA2576A9007B98CC/$File/AGDOS2011.pdf)

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Australian Government Department of Health and Ageing. (2004). *Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander Peoples: Resource Kit and Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander Peoples: Practice Principles*. Retrieved 6 May 2011 from <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-indig-resource.htm>

Australian Health Ministers' Advisory Council. *Advance care directives*. At the time of writing the project had not been completed. Details will be available in due course from <http://www.ahmac.gov.au/site/home.aspx>

CareSearch: an online resource of palliative care information and evidence. Retrieved 6 May from <http://www.caresearch.com.au/Caresearch/Default.aspx>

See too *CareSearch* for the impact of advance care planning. Retrieved 10 May 2011 from <http://www.caresearch.com.au/caresearch/FindingEvidence/PalliativeCarePubMedSearches/tabid/322/Default.aspx>

Commonwealth Respite and Carelink Centres. Retrieved 10 May 2011 from <http://www9.health.gov.au/ccsd/>

Clayton, J.M., Hancock, K.M., Butow, P.N., Tattersall, M.H.N. & Currow, D.C. (2007). 'Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of life-limiting illness, and their caregivers'. *Medical Journal of Australia*, 186, (12), S77 – S108. Retrieved 3 March 2011 from http://www.mja.com.au/public/issues/186_12_180607/cla11246_fm.html

HealthInsite. Links to information about services provided by information partner organisations, including state government health agencies, peak bodies, non-government organisations, some research organisations and hospitals. Retrieved 10 May 2011 from <http://www.healthinsite.gov.au/>



National Breast and Ovarian Cancer Centre. *PCAC – Cancer – How are you travelling. Understanding the emotional and social impact of cancer*. Retrieved 3 March from <http://www.nbocc.org.au/view-document-details/pcac-cancer-how-are-you-travelling>

National Health & Medical Research Council. (2008). *Post-Coma unresponsiveness and minimally responsive state: A guide for families and carers of people with profound brain damage*. NHMRC, Canberra. Retrieved 3 March 2011 from http://www.nhmrc.gov.au/health_ethics/ahec/postcoma.htm

National Health & Medical Research Council. (2005). *Guidelines for a Palliative Approach to residential aged care*. NHMRC, Canberra. Retrieved 3 March 2011 from <http://www.nhmrc.gov.au/publications/synopses/ac12to14syn.htm>

Palliative Care Australia. (2004). *The hardest thing we have ever done: The social impact of caring for the terminally ill people in Australia*. Retrieved 21 February 2011 from <http://www.palliativecare.org.au/Default.aspx?tabid=2016>

Respecting Patient Choices® An Australian Model of Advance Care Planning. Retrieved 6 May 2011 from <http://www.respectingpatientchoices.org.au/>

State and Territory Public Guardianship Boards. Retrieved 3 March 2011 from <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-acat-stpgb.htm>

Further information

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