



Dear Colleague

The National Health and Medical Research Council (NHMRC) has pleasure in providing you with the Discussion Paper *Ethical Issues involved in transitions to palliation and end of life care for people with chronic conditions: A Discussion Paper for patients, carers, and health professionals*.

The Discussion Paper presents an examination of the ethical issues relating to the nature of resources which would assist people with a chronic condition (at any age), and those who care for them to make informed and collaborative decisions about the ethical matters that arise as the end of a person's life approaches but death is not yet imminent. Typically this is the last twelve months or so of life and the Discussion Paper calls this the transition phase.

We are interested in your views on the issues and questions in the Discussion Paper and would welcome any specific or general comments you wish to provide in your submission.

Details on how to make a submission are contained inside the cover page of the Discussion Paper. You will also find there a submission form for comments – please fill this out and send it in with your comments. The deadline for receipt of comments is Friday 8 January 2010.

If you know of anyone else who may be interested in the Discussion Paper please make them aware of this public consultation.

More information on the background, including membership of the sub group who developed the Discussion Paper and electronic versions, can be found at <http://www.nhmrc.gov.au/guidelines/consult/index.htm> or by phoning the Project Officer on (02) 6217 9070.

Yours sincerely

A handwritten signature in black ink, appearing to be "Warwick Anderson".

Prof Warwick Anderson  
Chief Executive Officer

12 October 2009

WORKING TO BUILD A HEALTHY AUSTRALIA

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**ETHICAL ISSUES INVOLVED IN THE TRANSITIONS  
TO PALLIATION AND END OF LIFE CARE FOR  
PEOPLE WITH CHRONIC CONDITIONS:**

**A Discussion Paper for patients, carers  
and health professionals**

**Public Consultation**

**October 2009**

## **An invitation to provide comments on a Discussion Paper**

National Health and Medical Research Council (NHMRC), under paragraph 13 (d) of the *National Health and Medical Research Council Act 1992*, is seeking comments from interested organisations and individuals on this Discussion Paper (the Paper), released for public consultation. The Paper presents an examination of the ethical issues involved for people with chronic conditions, who face transitions in care as the final phase of life is approaching, but death is not yet imminent – typically the last twelve months of life. The Paper calls this the transition phase. NHMRC also seeks comments from families, loved ones, carers, and health professionals who care for people in the transition phase.

The Paper has been developed the Australian Health Ethics Committee (AHEC) through an expert AHEC Sub Group. Details on membership of the group, and the Paper itself can be found at <http://www.nhmrc.gov.au/guidelines/consult/index.htm>

The results of the public consultation process will assist NHMRC and AHEC to identify and develop resources to assist people with a chronic condition experiencing the transition phase, (and those who care for them), to reflect upon, and make informed decisions about, the many sensitive ethical matters associated with the transition phase. For example, changes in the place and type of care required, and withdrawal of burdensome treatment.

### **How to provide comments**

Questions are provided throughout the document (in boxes) to stimulate debate and encourage thinking about the issues presented. You may wish to frame your comments in response to these questions – although please note it is not necessary to answer all, or even any, of the questions. In responding to a specific question or section, please list the number in your response (numbers are to be found in the top left hand corner of each box of questions). Comments on any other aspects of the Paper are welcome.

In particular, NHMRC and AHEC are interested in the nature and content of resources which you or your organisation consider would be helpful in informing the ethical decisions that need to be made in times of transition. For example, guidelines may be considered the most appropriate resource? NHMRC welcomes your comments on the questions posed in the Paper, suggestions as to other questions (and answers) which you or your organisation consider relevant to include and comments or suggestions on any other matters raised in the Paper.

In addition you may choose to bear in mind the following questions while framing your response:

- Have any issues been overlooked?
- Do you suggest any changes to material?
- Are the issues presented understandable?
- Does the Paper provide an accurate reflection of the current issues most relevant to the topic?
- Is the range of issues covered appropriate?

**Copies of the Discussion Paper are available from**

<http://www.nhmrc.gov.au/guidelines/consult/index.htm>, or can be obtained by phone or email as listed below.

A form seeking authorship and other details is included in this document (pages 4-5). It is also available on the NHMRC website. Please complete and attach the form to your submission.

**Submissions that do not have the completed, signed form will not be accepted.**

For emailed forms, entering your name into the signature field is sufficient as a signature.

Electronic submissions are strongly preferred. Alternatively, please provide your comments in writing (preferably typed or word processed) or on audio tape.

Please send your comments:

By email to: [ethics@nhmrc.gov.au](mailto:ethics@nhmrc.gov.au)

or by mail to:

Project Officer, Transitions  
Health and Research Ethics Section  
Quality and Regulation Branch  
NHMRC  
GPO Box 1421  
CANBERRA ACT 2601

**Closing date: 8 January 2010**

Please draw this opportunity to the attention of anyone whom you believe would be interested in providing comments.

**Consultation Submission Form**

**PLEASE COMPLETE AND SIGN THE FORM BELOW AND ATTACH IT TO YOUR SUBMISSION. SUBMISSIONS THAT DO NOT HAVE THIS FORM ATTACHED WILL NOT BE ACCEPTED**

**1. Does this submission reflect the views of the organisation or an individual?**

An individual  An organisation

**If the submission reflects the views of an organisation please include details of the organisation at #2:**

**2. Contact Details**

**Name:**

\_\_\_\_\_

**Organisation:**

\_\_\_\_\_

**Address:**

\_\_\_\_\_

—

\_\_\_\_\_

**Phone no:** \_\_\_\_\_

**Fax:** \_\_\_\_\_

**Email:** \_\_\_\_\_

—

**3. My submission is confidential/not confidential.**

CONFIDENTIAL  NOT CONFIDENTIAL

**(Please Note:** You should be aware that any submission made to the NHMRC may be subject to the requirements of the Commonwealth *Freedom of Information Act 1982*.)

**4. National Health and Medical Research Council (NHMRC) has my permission to place my submission about this consultation draft on the NHMRC website.**

**(Please Note:** NHMRC retains the right to determine whether or not it will post submissions on the NHMRC website.)

YES  NO

**5. NHMRC can include my name, and where relevant the name of the organisation I represent, with my submission on the website**

YES  NO

**6. NHMRC has permission to quote from my submission in any reports prepared about this document.** (If you do not agree to your submission being quoted, the issues you raised in your submission may be referred to. However, no direct quote would appear.)

**YES**

**NO**

I am aware that if I agree to release information from my submission, it will be widely available, e.g. it may be placed on NHMRC's website and made available in hard copy. I am also aware that the information may be further referenced in later publications. If I have named an organisation at number 2 above, I agree that my comments represent the views of the organisation.

Any personal information provided, e.g. contact details, will only be used for the purpose of developing this document and will only be disclosed to members of NHMRC's and AHEC. Such information will not be used or disclosed for any other purpose, without prior written consent.

Name (please print) \_\_\_\_\_

Signature: \_\_\_\_\_

(For emailed forms, entering your name into the signature field is sufficient as a signature).

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# 1. EXECUTIVE SUMMARY

Like the rest of the world, Australia is experiencing an increase in the incidence of chronic conditions. As the population ages, and as health care becomes more and more sophisticated, the incidence of those living with a chronic condition is also increasing.<sup>1</sup> There is a wealth of literature addressing various clinical, ethical and other aspects associated with care at the very end of life, i.e. when death is imminent. National Health and Medical Research Council (NHMRC), however, has identified a gap in the literature for the ethical issues that arise in the time leading up to this stage – the transition phase.

Whilst those with a chronic condition can live full and productive lives, sometimes for decades, there comes a point in time when it is apparent that the individual is facing the end of their life, even though death may not occur for some months. This realisation may come to anyone with a chronic condition and at any age. This Paper has identified that time as a transition phase, in other words the phase of life when individuals, their carers (professional or lay) and their families and loved ones become aware that the final phase of life is approaching, but death is not yet imminent. Typically, this time of transition involves a change in treatment and management of a chronic condition to palliative and other forms of treatment and care in what will be the final phase of life.

NHMRC and one of its Principal Committees, the Australian Health Ethics Committee (AHEC), has become aware that the ethical issues in times of transition are specific to that phase of life and that they are not necessarily the same as the ethical issues faced when death is imminent. This Discussion Paper (Paper) has been issued for public consultation with the intention of seeking the views of the community about the ethical issues at this time of transition and their views about the kinds of resources that would assist them in making associated decisions.

The target audience is deliberately broad so that as many views as possible can be sought about the exact nature of the ethical issues. It includes: individuals with a chronic condition (at whatever stage of illness progression or age); those who provide care for these individuals including health care professionals; non health care professionals such as lawyers and ministers of religion; and other non professional groups such as families, loved ones and volunteers. It is important to understand that this Paper, does not apply only to older Australians: the focus is the ethical issues for those of all ages who are facing the transition process.

In particular, the aim of this public consultation process is to identify the nature and extent of ethical issues surrounding transitions in (health) care towards the end of life for those with a chronic condition, across the life span, and to identify the kinds of resources that could be developed to support decision making about ethical issues at that time of transition. Discussions about these issues can be difficult to initiate and sensitive to conduct. NHMRC and AHEC intend that the resources to be developed will facilitate discussions and decision making (without replicating existing resources) and so enhance care as the transition phase progresses.

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<sup>1</sup> National Health Priority Action Council. 2006. *National Chronic Diseases Strategy*, Australian Government Department of Health and Ageing, Canberra.

Aside from the ethical issues, there are a great many considerations in the transition phase and this Paper does not cover all of them. Its focus is on the ethical issues, so other considerations are noted only when they have a direct bearing on the ethical issue being discussed. For example, the possible consequences for professionals working across jurisdictions with different legal requirements for advance care directives are noted and explained without being discussed in any detail. The Bibliography section of the Paper (pp35-40), includes references for further clarification for this specific issue and for other relevant issues.

The Paper is set out in three distinct sections – for details please refer to Section 1.3. Note that Section three of the Paper is the most comprehensive Section. It poses a series of example questions that might be included in resources developed to assist individuals facing the transition phase. The expectation is that submissions will identify whether or not these questions are likely to be useful in helping people to reflect on the ethical aspects of their situation and to make informed choices. In addition, respondents are invited to identify whether or not the questions sufficiently indicate how the ethical values and principles can be used to inform the decisions that need to be made about ethical issues in the transition phase. There is also the opportunity for respondents to add further questions – and a rationale for their inclusion.

Language is significant when discussing ethical issues: a word or a phrase can for instance convey a negative meaning that was not intended. Consequently, the Paper encourages feedback not only in terms of its content but also in terms of inclusive and respectful language (words and phrases) that may be used in any resources that are developed. This point is likely to be of particular relevance to Aboriginal and Torres Strait Islander people, for those from culturally and linguistically diverse backgrounds and perhaps for those of particular faith traditions or beliefs.

There is a Bibliography Section with citation details for the extensive research undertaken in preparation of the Paper and where possible it includes web based links. Section 5 consists of descriptions and / or definitions of the key terms used in the Paper and how they have been understood and applied by the AHEC Sub Group (includes web links). Section 7 has details of the functions of AHEC and section 8 lists the members of the AHEC Sub Group.

## 1.1 Background

This Discussion Paper (Paper) has been developed in response to matters that have been raised with NHMRC and one of its Principal Committees, AHEC. In relation to end-of-life health care issues, NHMRC is committed to the integration of research and clinical excellence. To that end, whole-of-NHMRC projects are underway in conjunction with the Department of Health and Ageing (DoHA) with a view to understanding the health care needs of older Australians, including those needing palliative care towards the very end of their lives.

For its part, AHEC has determined that ethical issues about health care of chronic illnesses or conditions as the end of life approaches are a pressing societal concern and within its remit of providing advice on health ethics matters to the NHMRC. In late 2008, a draft Issues Paper titled *Living within Limits: Ethical Issues for Those Ageing with a Chronic Illness* was circulated for targeted consultation. NHMRC approached 25 public and private organisations and individuals in this phase and a total of 15 submissions were received. The aim of the targeted consultation was to canvas community views and concerns about the ethical issues at the end of life for older Australians.

Feedback from this consultation process confirmed the importance of these issues within the Australian community. Subsequent research indicated that while there was a wealth of information on ethical issues at the very end of life, little attention had been given to the ethical issues involved in the many transitions in health care that occur towards the end of life, in particular the introduction of palliative care. The research also indicated that whilst the ethical issues were perhaps of most relevance for older Australians, they were also applicable to anyone of any age with a chronic condition, facing a transition from treatment and management of a chronic condition to palliative and other treatments in what will be the final phase of life. Palliative care, that is, care designed to promote well being, for example by relieving pain or distress, may be required up to twelve months before a person dies although it may not be the only form of care transition that is being contemplated by the individual concerned.

In this Paper, NHMRC and AHEC have decided to focus on the ethical issues surrounding the transitions that arise during what may be a significant period of time prior to death. It also decided to widen the focus to include not only older Australians but all of those with a chronic condition who, at whatever age, are facing transitions in care as the end of their life approaches.

## 1.2 Scope and Aims of this Discussion Paper

*‘By living with and learning to manage long term illness, many people develop a high degree of expertise and wisdom’<sup>2</sup>*

In developing this Paper, numerous ethical and clinical guidelines addressing palliative care and end-of-life issues have been identified. Some have been developed and published by NHMRC whilst others have been published by either national or international stakeholder organisations.<sup>3</sup> In preparing the Paper, the AHEC Sub Group also drew upon the expertise and wisdom that many people with a chronic condition come to acquire, expertise and wisdom that was reflected in submissions to the earlier targeted consultation process.

The aim of this public consultation process is not to replicate any of the plans, guidelines and / or specific programs and supports already available. Rather, submissions to this Paper will be used to identify the nature and extent of ethical issues about transitions in health care towards the end of life that existing resources do not address. Submissions will identify the kinds of resources and guidelines respondents consider to be appropriate and will also inform their subsequent development. The aim of whatever is developed will be to facilitate discussions and decision making about these same ethical issues with a view to contributing to positive transitions, at any stage of life, and thus to whatever peace and acceptance is possible at the end-of-life phase for all concerned.

## 1.3 Structure of this document

The Discussion Paper has been developed with the following structure:

Section 1 (this part) outlines the scope and aims of this Paper and its focus on ethics and end-of-life transitions in health care at any age. It includes the background to its development, the matters that led to its development, including details of a previous targeted consultation phase and details about the structure of the Paper itself.

Section 2 contains a brief explanation of the differences between ethical, scientific and technical matters, an outline of the ethical values and principles that act as the ethical framework for the Paper and introduces the concept of the ‘no surprises’ period to which this Paper is addressed. It also explains the rationale for the Paper’s focus on ethics.

Section 3 then presents the ethical priorities and values that have informed the development of the Paper. Following a discussion of each priority sample questions are presented to stimulate feedback on specific ethical issues. The questions are grouped around the broad headings of: respect for the value of autonomy and dignity; the standards and goals of health care; and acting in the best interests of the individual. Within those broad headings, questions are posed for three specific groups: individuals facing the transition; loved ones or carers; and health professionals.

The Bibliography contains citation details of the sources consulted in preparing the Paper.

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<sup>2</sup> Wilson, J. 1999. ‘Acknowledging the expertise of individuals and their organisations’ *BMJ* 319; 771-774, (p771).

<sup>3</sup> See Bibliography for citation details of these publications.

Section 5 contains important definitions of the terms used and the sources of those definitions.

Appendix A describes the role and functions of the Australian Health Ethics Committee (AHEC).

Appendix B lists the members of the AHEC Sub Group.

## 2. ETHICAL ISSUES INVOLVED IN TRANSITIONS IN HEALTH CARE TOWARDS THE END OF LIFE

### 2.1 Introduction

This Discussion Paper (Paper) explores key ethical questions that arise when an individual's health care needs change from treatment and management of a chronic condition to palliative and other treatments in what will be the final phase of life. At this time, individuals commonly face several 'transitions' – in the kinds of treatments they require and choose, in the healthcare professionals caring for them, in the places in which they receive treatment and care, and in their relationships to carers and loved ones. Times of transition involve new decisions about what is important to individuals about how they wish to be treated and cared for and by whom. Clarity about the ethical values at stake in these decisions can help to facilitate decision making and enhance patient focussed care.

The AHEC Sub Group is mindful of the tendency of the existing health care system to assume that:

*'...living and dying are discernibly different and that medical practitioners must either (1) apply aggressive conventional medical care to try to extend or save a person's life or (2) accept death and provide only palliative care.'*<sup>4</sup>

This Paper challenges the idea that 'living and dying are discernibly different', and supports the view that acute, curative medical treatments should be separate to palliative and other forms of care and treatment. Good management of health care for those who 'live with dying' often requires that palliative measures be introduced while an individual is still being treated for their current or long standing condition, and that 'advance planning' for care and treatment in the final phase of life is often appropriate while an individual is still relatively well. Palliative measures should not be reserved for the very last days of life. Communication between the various health care professionals is essential to the development of appropriate clinical pathways that will achieve the best outcome for an individual with a complex and deteriorating medical condition as they approach the end-of-life phase.

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<sup>4</sup> RAND Health. 2006 'Redefining and reforming health care for the last years of life'. Accessed from: [http://www.rand.org/pubs/research\\_briefs/2006/RAND\\_RB9178.pdf](http://www.rand.org/pubs/research_briefs/2006/RAND_RB9178.pdf) December 2008 (p2).

## 2.2 The Transition Phase – a ‘No-Surprises’ Period

*‘One of the greatest gifts in confronting death is the perspective it offers about living life’.*<sup>5</sup>

The AHEC Sub Group has accepted as a working definition of the period during which these transitions occur, what some experts describe as the ‘no surprises’ period. In arguing for the right to palliative care of all those with a chronic condition, Murray et al (2004) suggest we ask a simple question to determine whether or not early referral to palliative care would be beneficial.<sup>6</sup>

The question is:

*‘ “Would I be surprised if my individual were to die in the next 12 months?” And if the answer is no, we need to give the individual and his or her family an opportunity to plan for a good death, instead of just monitoring a downward set of physical variables until death.’’*<sup>7</sup>

While recognising that care decisions dictated by prognosis can never be definitive, this Paper will speak of the ‘no-surprises’ period as a span of about 12 months, during which the involvement of, or transition to, palliative and other forms of care will often be required. Although this transition may be triggered by a singular event, it may also occur gradually over a twelve month period that includes several critical events from which an individual recovers, though in a weakened condition. If it would not be a surprise for an individual to die in the next twelve months, then assessment of various scenarios and clinical pathways for end-of-life care should be undertaken.

At times, commencement of the no-surprises stage of a chronic condition may not be clear cut: there may be no precise time at which an individual knows (or is able to acknowledge) that the transition is actually happening. Some individuals may well not die within the 12 month period. But if death is reasonably foreseeable within the next 12 months (or year), then it is wise for this fact to be taken into account when planning for that individual’s health care needs.

The word ‘transition’ may not seem appropriate to those individuals who experience only gradual changes in the way they live their lives. Nevertheless, the AHEC Sub Group believes the word ‘transition’ is a good marker for what is commonly a time of significant change in the progression of an individual’s chronic condition, and in the decisions individuals and carers face at this time. Clearly, as the population ages and the incidence of chronic conditions increases, more and more older Australians will need to consider planning for this final phase of life.

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<sup>5</sup> McPhee, S.J., Rabow, M.W., Pantilat, S.Z., Markowitz, A.J & Winker, M.A, 2000, Finding Our Way – Perspectives on Care at the Close of Life, *Journal of American Medical Association*, Vol 284, pp 2512 – 2513.

<sup>6</sup> Murray SA, Boyd K, Sheikh A, Thomas K, Higginson I. ‘Developing primary palliative care: people with terminal conditions should be able to die at home with dignity.’ *BMJ*: 329: 1056-1057, 2004.

<sup>7</sup> Murray SA, Boyd K, Sheikh A. ‘Palliative care in chronic illness’. *BMJ* 350: 611 -612, 2005. Accessed from <http://www.bmj.com/cgi/reprint/330/7492/611> 31 March 2009 (p612).

The no-surprises period is not confined to older Australians. Accordingly the AHEC Sub Group recognises that the timing of palliative care for children and young people is influenced by the diagnostic diversity and prognostic uncertainty in their case. Unlike the usual adult population receiving palliative care, approximately 40% of children in palliative care have a malignant condition.<sup>8</sup> It is unclear if the transition phase for children and young people can be considered to be a twelve month period as the commencement of the period may occur quite suddenly given the range of illnesses that specifically affect children and young people. Notwithstanding that consideration, the ethical issues in this Paper apply equally to those in the no surprises phase, whatever their age and stage of life.

## 2.3 Focus on Ethics: Rationale

Health care decisions always involve ethical issues, most obviously in relation to beginning or ceasing particular treatments. These issues can become more urgent when an individual realises that their life is entering its final phase. The issues include facing one's own mortality – or, in the case of some, facing the mortality of a loved one who can no longer express their own choices and preferences. Research indicates that the issues of concern include coming to a sense that one's life, in its broadest and most inclusive sense, has been meaningful, that one is leaving behind some 'legacy', and that one is 'at peace with God' – however this is understood by the individual concerned (Steinhauser et al, 2000).<sup>9</sup> The reality of death gives rise to issues that may not have consciously arisen before, but as the end of one's life approaches, they must now be faced (Daaleman & Creek 2000).<sup>10</sup> With that realisation, come questions about the appropriateness of continuing medical treatments aimed at cure, about the meaning and likely benefits of treatments compared to their burdens, and about how death might best be understood in relation to life.

The prospect of foreseeable death provides the opportunity for individuals to make critical healthcare decisions about how they wish to live the last stage of their life, however long or short that may be. For example:

- Decisions about the individual's continuing control of the condition, the resultant wellbeing the individual experiences and his or her ability to function.
- Decisions about the extent and limits of available health care treatment in relation to life sustaining and / or life prolonging measures, including locations and accessibility of where that treatment is provided.
- Decisions about the nature of the relationships the individual wants to sustain at this time, including how individuals want to order their lives and relationships with others so as to make the transition to their death meaningful in their own way.

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<sup>8</sup> Royal Children's Hospital *Victorian Paediatric Palliative Care Program* 'Transition to palliative care.' Accessed from: [http://www.rch.org.au/rchpalliative/?doc\\_id=1710&print=yes](http://www.rch.org.au/rchpalliative/?doc_id=1710&print=yes) 12 March 2009.

<sup>9</sup> Steinhauser K E, Christakis N A, Clipp E C, McNeilly M, McIntyre L, Tulsky J A. 2000. 'Factors considered important at the end-of-life by individuals, family, physicians and other care providers. *JAMA* 284: (19) 2476 – 2482.

<sup>10</sup> Daaleman T, Van de Creek L. 2000. 'Placing religion and spirituality in End-of-Life care'. *JAMA* 284: (19) 2514 – 2517.

The obviously clinical issues that arise during this transition phase, e.g. relief of pain, cessation of aggressive treatments and so on, are never merely 'clinical'. Good health care treats an individual person, not a condition. Clinical issues are in fact shaped by considerations that are ethical, social, cultural, spiritual and metaphysical in nature. Sound ethical reflection on issues such as the burdens of a treatment relative to alternatives, the distinct responsibilities of health professionals and carers, and the justice of resource allocation, help to clarify and facilitate good clinical decisions. This Paper highlights the holistic nature of the transitions people face in the final phase of life, involving as it does, matters to do with medical treatments, places of care, access to specialist (palliative) care and the availability of resources to maximise the choices of the individual concerned.

For those who have lived happy and fulfilling lives with a chronic condition, sometimes for years, the recognition of the need for a transition to palliative and other types of care can be challenging because it signals a marked change in the status of the condition, usually a deterioration of some kind. Fears and concerns are likely to arise about the next phase of the individual's life, including the prospect of losing control over how they live their life in its final stages.

Whilst the final stage of life, and dying itself, is an intimately personal experience, there are usually others who accompany the individual as the end of their life approaches, be that as a family member, a loved one, a carer, a friend, a neighbour or as a professional. These people too may also be faced with new decisions about how they want to shape their conduct, attitudes and emotions in this phase, both towards the individual making the transition (for whom they may also be providing care), and for their own sense of meaning and fulfilment at this time in their life.

There may also be distinctive ethical considerations about preparing for death that are specific to particular groups in our community with special needs, such as Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse communities, those who are ageing, those with a disability, carers (paid or unpaid), and health care professionals.

## **2.4 The Nature of Ethically Based Questions**

Questions of an ethical nature need to be distinguished from evidence-based, technical or scientific questions. For example, questions about the likely effects of a particular treatment are matters for scientific judgment. Likewise, how a treatment is to be delivered is a technical, medical issue. Whether or not a treatment should be provided at all, however, depends on ethical considerations – for example, about whether the treatment will benefit a particular individual in his or her actual situation, or whether the treatment would be regarded by the individual as unduly burdensome for them or for others, such as loved ones. These ethical considerations are informed by scientific evidence and the exercise of (professional) skills and expertise, but the decisions made on the basis of these considerations are properly ethical, and not merely technical or scientific.

The ethical considerations at times of transition in health care are frequently sensitive and complex, and are usually influenced by cultural and religious values and beliefs. It can be difficult for individuals to raise matters that concern them about such values and beliefs, or to articulate what this new experience means for them and how they want to manage it. Although people's questions and decisions will be individually unique, there are well recognised ethical considerations that will shed light on those decisions and offer reassurance and self-confidence. Clarity about the ethical aspects of transitions in health care should help individuals, carers and professionals to think through the various options for treatment and care in the final stages of life. Conversations about these issues can also be a valuable preparation for dying and contribute to the sense of hope and / or closure that can make the last phase of life fulfilling.

## **2.5 Ethical Issues for Health Care Professionals**

Transitions in health care toward the end-of-life frequently signal a need for palliative care as an integral part of active treatments and existing care, e.g. palliative care may be an addition to existing care and management of chronic pain and is not restricted to the very end of life. The introduction of palliative care in the management of a person's condition can be challenging for health care professionals because it commonly signals the changing needs of the person, the need to review existing care regimes and treatments, the involvement of different professionals in the person's care, and the inevitability of death.

Early referral to palliative care professionals is recommended in order to maximise the control of symptoms and enhance the wellbeing of the patient, including his or her lucidity and ability to function and the provision of the most appropriate care for the transition phase. Palliative measures are often essential to the continuing management of a chronic condition and contribute to maximising wellbeing for the individual concerned. Good communication and appropriate referrals between acute care services and palliative care services are essential. Likewise careful and comprehensive documentation is necessary to ensure that the individual receives the best possible care should they be transferred between care locations or facilities. Often it is the individual's general practitioner who becomes the common reference point between all health care professionals involved. Referral when the individual has only a few days to live is likely to diminish the effectiveness of care and may cause increased burdens of pain and suffering for the individual and their loved ones.

Questions about keeping control, fear about how death will occur, the meaning of life and death, and about personal autonomy, often lead to debate about the issue of euthanasia and assisted suicide. Whether euthanasia – the deliberate ending of a person’s life by act or omission – is ever ethically permissible, and / or whether it should be legally permissible, are contentious issues in the Australian community. The right of all Australians to access good palliative care services is pivotal to the circumstances which drive the euthanasia debate. Popular opinion is often hampered by misunderstandings about the difference between euthanasia on the one hand, and the withdrawal or the withholding of overly burdensome treatment on the other hand, as well as by anecdotal reports of both under-treatment and over-treatment as death approaches. Inconsistencies in the provision of palliative care across the country also compound debates about euthanasia.

Development of strategies and processes to enhance communication between health care facilities, ways of ensuring continuity of care and team approaches to care is essential because GP’s, nurses, specialist nurses and physicians have crucial roles to play in times of transition.<sup>11</sup>

### **3. ETHICAL PRIORITIES IN TIMES OF TRANSITION IN HEALTH CARE**

Ethical considerations derive from ethical *values, principles* and *standards* of conduct – those applicable to health care professionals in particular, as well as those values, principles and standards applicable to all human beings.

The AHEC Sub Group suggests that special attention to the following ethical priorities is the key to good (ethical) decision making about transitions in health and health care for individuals with chronic conditions:

- The value of personal autonomy.
- The standards of good health care.
- The principle of acting in the best interests of the individual.
- The value of justice in the use of resources.

This Section briefly explains the relevance of these ethical priorities to transitions in treatment and care. It also identifies questions that may assist the application of these values to the decisions faced by individuals, carers and health care professionals, in relation to the transition to palliative and / or other forms of care.

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<sup>11</sup> Meier D & Beresford L. 2008. ‘Palliative care’s challenge: facilitating transition of care’. *Journal of Palliative Medicine*, 11:3, 416 – 421.

## 3.1 Respect for the Value of Personal Autonomy and Dignity

### Respecting others

Respect for others recognises the fundamental value of each human being, no matter what their age or health status. In the case of the transitions in health and health care, e.g. a transition to palliative care, respect for individuals should exclude any form of discrimination. Discrimination could include 'ageism', which would imply that people who are older or chronically ill are less worthy of treatment than other people.

The concept of respect as articulated in the *National Statement on Ethical Conduct in Human Research (National Statement)* (2007) is also applicable to respect for those who have a chronic condition.

*'... respect... involves recognising that each human being has value in himself or herself, and that this value must inform all interaction between people. Such respect includes recognising the value of human autonomy – the capacity to determine one's own life and make one's own decisions. But respect goes further than this. It also involves providing for the protection of those with diminished or no autonomy, as well as empowering them where possible and protecting and helping people wherever it would be wrong not to do so.'* (p11)

### Respect for personal autonomy

Personal autonomy is highly valued in Australian society and culture. In the context of health care decisions, respect for autonomy means recognising that the individual is the ultimate source of decisions about treatment and care. Personal autonomy presupposes the capacity to make choices that are free from coercion (implicit or explicit) or undue influence. By extension, it also means having a right to the knowledge necessary to make informed choices. At times of transition in health and health care, respect for the wishes of the individual should be paramount, so that they are involved in their own health care decisions as much as is possible.<sup>12</sup>

### Dependence and independence

Autonomy is linked to another ethical consideration, that of personal independence (sometimes called 'autarkia' – also 'autarky'). This is an '...ancient Greek term meaning self sufficiency' and indicates a capacity to care for yourself.<sup>13</sup>

'Self-sufficiency' extends the notion of autonomy to encompass this wider notion of an 'independent' life that is personally fulfilling (autarky) because one is actually able to make *and* act upon one's own choices (autonomy). The loss of 'self sufficiency' and 'independence' (autarky) need not mean the loss of autonomy as individuals may be entirely autonomous but at one and the same time, entirely dependent on others e.g. in carrying out acts of daily living. Individuals with a chronic condition are often capable of making their own health care decisions, even if they cannot physically carry them out because they are becoming more dependent on others (the loss of autarky). The classic example of this

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<sup>12</sup> Australian Nursing and Midwifery Council, *Code of Ethics for Nurses in Australia*, 2008, and Australian Medical Association, *Code of Ethics*, 2006.

<sup>13</sup> Audi R. 1999. *The Cambridge Dictionary of Philosophy*. Cambridge University Press (p 62).

conundrum is the individual with quadriplegia who, while autonomous, completely lacks autarky because she or he is entirely dependant on others.

Although the fear of losing autonomy and / or independence is often real and profound, dependency is always a feature of human life: human beings begin their lives totally dependent on others, and they remain inter-dependent throughout their lives. Individuals with a chronic condition often come to accept the limitations of their condition and of their dying as contexts in which they can welcome the love and respect people have for their intrinsic dignity, regardless of any limitations imposed by their condition.

The capacity for autonomy can be transitory, existing at some times and not at others. It is also the case that a person may still be able to make decisions that are authentically their own decisions even though they are cognitively impaired. For example, a person with dementia may be unable to recall recent events, but may still be able, with assistance, to appreciate her circumstances in a momentary way and make a decision that authentically reflects her own values, even if she may, in the next instant, forget the circumstances or even having made the decision.

When individuals begin to need to make a transition in their health and health care needs, e.g. a transition to increasing dependence and / or palliative care, they normally re-consider their relationships with their loved ones. They can be troubled about being a burden to others, but they also need other people. They also wish to celebrate what is most important in their relationships, and give meaning to their death and to the 'legacy' that they will leave behind.

Many cultures are less individualistic than modern industrial cultures tend to be: they have different interpretations of the place of autonomy and 'self-sufficiency' in a fulfilling and flourishing life. For example, in contrast to the individualistic interpretation of autonomy, Aboriginal and Torres Strait Islander peoples emphasise relationships which are reciprocal and based on concepts of mutual obligation.<sup>14</sup> Many cultures value a family hierarchy of decision-making, based on gender or seniority, while the Chinese value of filial piety embraces the value of children supporting their parents.<sup>15</sup>

These differences need to be taken into account in decision making processes as individuals experience transitions in their health care, e.g. in the 'no surprises' phase of their lives, a phase which may include a transition to palliative care.

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<sup>14</sup> NHMRC. 2003. *Values and Ethics: Guidelines for Aboriginal and Torres Strait Islander Health Research*.

<sup>15</sup> Chiung-Hin Hsu O'Connor, Margaret, Lee Susan. 2009. 'Understandings of death and dying for people of Chinese origins'. *Death Studies* 33:153-174

## Advance Care Planning

Individuals with a chronic condition often, rightly, want to be involved in planning for their future health care needs, especially when they anticipate being unable to make their own decisions. Integrated health care plans (incorporating advance planning) should be holistic and may need to include treatment of inter-current health problems. They should, however, emphasise hope and living well, and dispel any perceptions that palliative care equates with imminent death.

Advance care planning enables an individual to provide guidance or instructions about future decisions, if and when they become unable to make such decisions. This may simply involve discussion with family, friends, professionals and other carers. On the other hand, an individual may also appoint someone to be their 'representative'. Someone may become an individual's 'representative' in three ways: when appointed by the individual before he or she became incapable; when appointed by a court or tribunal; or automatically by legal statute (e.g. as a person responsible or as a senior next of kin).

An Advanced Care Directive is stronger than a statement of wishes, since it is intended to be binding in certain specific circumstances. In some jurisdictions, advance care directives can have a legal status requiring compliance by caregivers in relation to refusal of treatment. To apply an advance care directive, the health care professional needs to be satisfied that the directive applies to the actual circumstances of the individual's condition and care.

NHMRC is aware of work being done on advance care directives by the Australian Health Minister's Advisory Council with a view to developing national guidance on advance care directives

### **3.1.1 Questions about Autonomy and Dignity for Consultation Feedback**

The way that ethical considerations are brought to bear upon individual situations is through decisions of the people concerned. Some matters are more relevant to individuals in transition, others to their carers and families and still others to health care professionals.

The following questions are proposed as the kind of questions that individuals, carers and families and health professionals might ask themselves in relation to the value of personal autonomy. The questions are meant to be examples of questions that might be included in resources to assist individuals facing these transitions in health care. The AHEC Sub Group would like to know whether questions like these:

- are likely to be useful in helping individuals to reflect on the ethical aspects of their situation and to make informed decisions; and
- help to show how this ethical value can be used to inform the decisions that need to be made in times of transition.

#### **Sample questions for people facing transition**

- a) What changes in my current circumstances are likely to occur as a result of changes in my health care e.g. changes in my living arrangements?
- b) How will changes in my condition and treatment result in changes for other people?
- c) How can I preserve my autonomy and sense of fulfilment, even if I become more dependent on others?
- d) How and when can I begin to talk with loved ones about my eventual dying in a way that is culturally appropriate for me and for them?

#### **Sample questions for loved ones or carers**

- e) What would the individual and / or my family want in these circumstances?
- f) In relation to family involvement, how will we go about planning to support our family member?

#### **Sample questions for health care professionals**

- g) Have I provided the information needed to help the person decide whether or not a proposed treatment would be beneficial?
- h) Should this person be encouraged to develop an advance care plan, given the likelihood of death within the next twelve months?
- i) Have I appropriately documented these discussions?
- j) How can I preserve an individual's autonomy even when they have lost autonomy?

Are there any other questions you would suggest?

## 3.2 The Standards and Goals of Health Care

### The limits of medicine and the acceptance of death

The overriding goal of medical interventions and health care is to help people sustain the life and health that is fundamental to their total well being, including their ability to make their own decisions and to live independently (autarky). Critical to good health care is recognition of these proper goals: 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 disease, or relieve distressing symptoms. Recognition of the proper and limited goals of health care includes judging when a treatment is no longer beneficial, and when the time has come to accept the inevitability of death, while continuing to keep a person as free of pain and other suffering as is possible, and providing ordinary life-sustaining care.

Ethical reflection on the goals of health care can facilitate decisions during transitions – for example, by helping to identify futile treatments, to distinguish curative treatments from palliative treatments, to distinguish ordinary life sustaining treatments from aggressive and burdensome treatments, and by clarifying the significance of the burdens associated with treatment.

### Evaluating risks, burdens and benefits

It is always necessary to evaluate the therapeutic benefit of an intervention, and thus whether it would be overly burdensome or futile. Decisions about treatment should take into account the burden for the individual, but may also need to take into account the impact on the family and community. The individual – or their appointed decision maker – is always the one who decides whether a treatment is burdensome for them or not.

Treatments are futile if they bring no benefit to the individual. Treatments may be judged to be overly burdensome by the individual concerned when they judge that the burden of treatment for them is disproportionate to the likely benefits. Whether a particular treatment is overly burdensome is determined by assessing and balancing the risky, intrusive, destructive, exhausting, painful or repugnant nature of the treatment, against its benefits or reasonable chance of success.

Such decisions need to consider:

- The individual and family's particular circumstances, experience of illness and its remedies, and culture, beliefs and preferences; and
- The burden or cost of the treatment and the availability of resources for the family and / or the community.

While palliative care aims to benefit all concerned, it focuses on the needs of the individual person. In relation to advance care plans, determining what would be a benefit and what would be a burden (or a harm) is a decision that is ideally made by the individual concerned in partnership with the health care team and other carers. When individuals are unable to do so, their representatives have a special role in assisting those responsible to determine what the individual would have wanted in the circumstances. The nature of what is an acceptable benefit and what is a burden may change for the individual as their condition becomes progressively worse and there is a need to discuss (and revise) care plans and perhaps the

context or environment for the delivery of that care. Approaches to these (potentially) challenging conversations can be initiated by anyone involved at any time.<sup>16</sup>

Individuals from Aboriginal and Torres Strait Islander communities<sup>17</sup> and those from culturally and linguistically diverse communities may have special needs in relation to decision making about burdens and benefits.

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<sup>16</sup> 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 a life-limiting illness and their care givers.' *Medical Journal of Australia*. 186: 12, S76- S108.

<sup>17</sup> McGrath et al. 2008. 'Insights on end-of-life ceremonial practices of Australian Aboriginal peoples'. *Collegian* 15, 125-1

### **3.2.1 Questions about Standards and Goals of Health Care - for Consultation Feedback**

The way that ethical considerations are brought to bear upon individual situations is through decisions of the people concerned. Some matters are more relevant to individuals in transition, others to their carers and families, and still others to health care professionals.

The following questions are proposed as the kind of questions that individuals, carers and families and health professionals might ask themselves in relation to the standards and goals of health care. The questions are meant to be examples of questions that might be included in resources to assist individuals facing transitions in health care. The AHEC Sub Group would like to know whether questions like these:

- are likely to be useful in helping individuals to reflect on the ethical aspects of their situation and make informed decisions; and
- help to show how this ethical priority can be used to inform the decisions that need to be made in times of transition.

#### **Sample questions for people facing transition**

- a) Am I getting enough out of this treatment?
- b) How will I know when to limit or withdraw a particular treatment?
- c) How do I find out what is available and if this is sufficient support for me and for those around me?
- d) How will this treatment now impact on my later condition? Will I be worse off in the long run?

#### **Sample questions for loved ones or carers**

- e) Am I the best person to be providing care for this individual? If I am not, then what do I need to do about it?
- f) Am I caring for my own needs even as I care for my family member?

#### **Sample questions for health professionals**

- g) When should the goal and scope of treatment options change from 'cure' to focus on relief of symptoms and assisting the patient to be able to best enjoy his or her remaining capacities without the burdens of curative attempts during the dying phase?
- h) Have I appropriately documented these discussions?
- i) When should the advice of other colleagues, for example palliative care experts, be sought? And is this referral/s handled in a way to be of least burden to the individual concerned?

Are there any other questions you would suggest?

### 3.3 The Principle of Acting in the Best Interests of the Individual

The guiding principle for health care professionals of always acting in the best interests of the individual is also associated with the long standing principle of non-maleficence, and the traditional professional maxim *Primum non nocere* ('above all do no harm'), which emphasises the protection of the individual. It can sometimes be difficult for physicians working with older individuals to understand their complex needs and to benefit them by prioritising care provided.<sup>18</sup> Frequent and open communication is essential. Decisions about what is in an individual's 'best interests' are best made by the individual concerned – or by their representative, or by both – in partnership with the whole of the care team, professional and non professional. These decisions need to respect the individual's own beliefs and values, and the things he or she holds to be most important, even if these differ from the family's or health care professional's views. Decisions also need to respect cultural or religious beliefs, and the special needs of groups such as Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse communities, and those with a disability. The decision also needs to be carefully documented in order to record the individual's wishes and to prevent the need to go through the decision making process again, especially when that process itself creates unnecessary burdens.

Decisions need to respect the individual's wishes about treatment, if they are known. This is not always straightforward. It is easier to be sure if the individual had written them down somewhere, or if the family can recall particular situations where the individual said, for example, 'I wouldn't want that for myself'. It is also important to know whether the individual was making a well-informed, rational, considered decision, or was perhaps depressed at the time, or coerced by others. To an active healthy person, what may prospectively seem an unacceptable level of disability or dependence on others, may in fact be acceptable when an individual is actually in that situation. What the family thinks and wants is also relevant, but only if it is clear that this is in line with what the individual would have wanted.<sup>19</sup>

Where nothing is reliably known about the wishes or preferences of the individual being cared for, and she or he is no longer capable of expressing those preferences, the principle of acting in their best interests will be applied by their representative. Here, the judgment is likely to be guided by empathy and compassion for the individual. Decision-makers may need guidance and support in clarifying and maintaining a focus on the best interests of the individual, not the interests of others involved, including family members and health care professionals or carers.

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<sup>18</sup> Nortvedt et al 2008. 'Clinical prioritisations of healthcare for the aged – professional roles'. *Journal of Medical Ethics*, 43, 332-335.

<sup>19</sup> NHMRC, 2008, *Post-Coma unresponsiveness and minimally responsive state: A guide for families and carers of people with profound brain damage*, p 19.

### **3.3.1 Questions about Acting in the Best Interests of the Individual - for Consultation Feedback**

The way that ethical considerations are brought to bear upon individual situations is through decisions of the people concerned. Some matters are more relevant to individuals in transition, others to their carers and families, and still others to health care professionals.

The following questions are proposed as the kind of questions that individuals, carers and families and health professionals might ask themselves in relation to the principle of acting in the best interests of the individual. The questions are meant to be examples of questions that might be included in resources to assist individuals facing these transitions in health care. The AHEC Sub Group would like to know whether questions like these:

- are likely to be useful in helping individuals to reflect on the ethical aspects of their situation and make informed decisions; and
- help to show how this ethical value can be used to inform the decisions that need to be made in times of transition.

#### **Sample questions for people facing transition**

- a) Have I expressed my wishes clearly?
- b) Do I need to appoint a representative?

#### **Sample questions for loved ones or carers**

- c) Do I have sufficient resources to provide the care required, e.g. lifting machines, and if not, how do I go about getting them?
- d) Is the overall care being well coordinated even if there are a range of services involved?
- e) How do I sort out what are the best interests of the individual from the interests of family and carers?

#### **Sample questions for health professionals**

- f) Is the individual being cared for in the most appropriate setting? If not, how will this choice be negotiated / respected?
- g) Should specialist palliative care advice now be sought?
- h) Is the individual's General Practitioner and other relevant (health care) professionals being involved in the individual's care, even if they are in an acute hospital?

Are there any other questions you would suggest?

### **3.4 The Value of Justice, Especially in Regard to Resource Allocation**

#### **Allocation issues**

The value of justice embraces many aspects of health care provision – firstly, in relation to the individual concerned, for example, by avoiding both under treatment and over treatment (heroic treatment), by preventing harm due to the use of multiple drugs, and by ensuring that individuals receive treatment in the setting most appropriate to their current needs. Health care professionals work within the context of a health care system whose resources are finite and justice towards other people may sometimes mean that treatments cannot be given to individuals because they would offer little benefit.

In the transition phase, difficult questions may arise about where a person should be treated – for example, at home, in an acute care facility or in a nursing home. It also raises questions about the level of care that should be provided. At times, individuals only need access to a particular service in an acute care facility e.g. a specialised test. In this instance individuals should be able to access services in some capacity that does not demand the full extent of clinical pathways normally required by the acute facility. 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 in these matters requires good communication between health care professionals, and clear pathways for management of the individual 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 and palliative care services and specialist nurses and medical personnel is limited. Likewise, individuals from population groups with particular needs can also be disadvantaged by resource issues. It is not fair or just to deny reasonable access to (specialist) 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. The inequitable distribution of resources places unfair burdens on those who live and work in rural and remote areas.

Another potential injustice may arise when culturally appropriate practices for the transition phase 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 individual's community to maximise choices and enhance understanding. The provision of these resources does of course have a cost although it is potentially inequitable to deny access simply because of resource allocation difficulties.

#### **Resources and carers: paid and unpaid**

Issues for carers are many and varied, and differ according to the nature of the relationships they have with the individual being cared for: e.g. a family member is likely to have different issues to those of a carer who is paid. In turn, the carer who is not paid and is not a family member, e.g. a volunteer, will have separate issues as well.

For unpaid carers who are also family members the impact of caring for individuals in the last phase of their lives can be severe. It may include financial burdens (giving up a job for

instance), social isolation and poor health through stress and physical injury. Family carers need information about their loved one's condition and the possible impact of the transition phase on the individual and on them as the carer of that family member. Family carers also need to be included as part of the care management team. In addition, they are likely to need support for the emotional and other issues that arise for them as their loved one progresses through the transition phase, e.g. feelings of guilt at no longer being able to provide care, compounded perhaps by the need to move the family member into another care context such as a nursing home.

Additional factors that unpaid carers face include: issues to do with 'burnout'; many carers are ageing (as are those they care for); and many (family) carers tend not to care sufficiently for their own needs.

Lack of resources broadly, and in rural and remote areas specifically, raise other issues, e.g. in terms of providing appropriate respite care and / or supports for carers. Lack of access and remoteness can compound an already stressful time. For instance, the need to travel long distances either to access care or to maintain relationships with a loved one who can no longer be cared for at home.

Paid carers, who are not fully qualified health care professionals, e.g. 'home help' and personal care assistants, may not have sufficient training or education to provide an acceptable standard of care to the level required by the individual, yet they may be the only source of care giving that is available. This raises issues to do with training, safety and quality – for them and for those receiving the care. The issues faced are similar to those faced by unpaid carers, although because they are employed, there are legal expectations, protections, and requirements such as occupational health and safety standards and benefits that do not apply to unpaid carers.

Unpaid carers who are volunteers face similar issues to paid carers, yet they also face the same kinds of issues as family members. Volunteers who work in palliative care services are usually well supported by the team in which they work: their role is highly valued in that they provide different support from health care professionals and often have more time to listen to the individual and their family. The status of volunteers though, may in some places, be less clear than that of health care professionals, yet the requirements for them to act in order to maximise benefits and prevent harms is similar to the broad expectations of health care professionals, albeit at a different level. Safety and quality of care provided as well as Occupational Health and Safety issues also apply.

### **3.4.1 Questions about Justice - for Consultation Feedback**

The way that ethical considerations are brought to bear upon individual situations is through decisions of the people concerned. Some matters are more relevant to individuals in transition, others to their carers and families and still others to health care professionals.

The following questions are proposed as the kind of questions that individuals, carers and families and health professionals might ask themselves in relation to the value of justice in resource allocation. The questions are meant to be examples of questions that might be included in resources to assist individuals facing these transitions in health care. The AHEC Sub Group would like to know whether questions like these:

- are likely to be useful in helping individuals to reflect on the ethical aspects of their situation and make informed decisions; and
- help to show how this ethical value can be used to inform the decisions that need to be made in times of transition.

#### **Sample questions for people facing transition**

- a) Do I consider that I am becoming a burden to others and how do I feel about that?
- b) How can I encourage my loved ones to continue with their own lives, even as they continue to care for me?

#### **Sample questions for loved ones or carers**

- c) What educational and training resources are available to me to assist me in giving high quality care?
- d) Do I know what I am entitled to in relation to Government financial support for being a carer? If not, how do I go about accessing that support?

#### **Sample questions for health care professionals**

- e) How can the community be sensitised to what can be expected when life is drawing to a close?
- f) How may health care professionals engage in a meaningful and beneficial fashion with an articulate and more empowered public and to what end?

Are there any other questions you would suggest?

## 4. CONCLUSION

This Paper has sought to highlight the ethical aspects of the decisions that people with a chronic condition commonly face towards the end of their lives. For these individuals, the last year or so of life often involves transitions in health care and in the circumstances in which it is provided. The Paper seeks to avoid any sharp distinction between acute medical treatments on the one hand, and palliative and supportive treatments and care, on the other hand. In the transition phase, both kinds of care and treatment are often needed.

The Paper has identified ethical priorities that the AHEC Sub Group believes are central to ethically sound decision making and effective clinical care. The priorities are respect for the value of autonomy and dignity, the standards and goals of health care, and acting in the best interests of the individual.

Through this public consultation phase the AHEC Sub Group invites respondents to comment on whether these ethical priorities are central, whether the sample questions associated with each priority are appropriate, and to suggest any other ethical considerations or questions which they believe to be equally relevant.

The AHEC Sub Group therefore invites a wide ranging response to these issues. For example, Is this document comprehensive enough? Are there parts of the document that are not relevant to the issue/s we should be concerned with? Respondents' answers to these questions, and their reflections on the sample questions in the body of the Paper, will assist the Working Party to identify the kind of resources, and the content, that might be developed to assist both individuals, carers and healthcare professionals as they deal with transitions in health care towards the end of life for those individuals with a chronic condition.

## 5. Definitions of Key Terms and Resources

### 5.1 Definitions and Key Terms

The AHEC Sub Group has drawn on the following definitions of key terms and concepts central to the discussion in the Paper. This section presents information about chronic conditions, as well as the AHEC Sub Group's understanding of key terms as presented in the definitions.

Feedback about the definitions is sought, for example, are they sufficiently inclusive of special needs groups such as Aboriginal and Torres Strait Islander peoples, people with disability, individuals with specific religious needs and / or those with culturally specific needs?

NOTE. The word 'transition' in this Paper is not to be confused with the Australian Government funded program, the National Transition Care Program. For further information about this Program refer to 5.2.4.

#### 5.1.1 Palliative care

The AHEC Sub Group notes the short definition of palliative care which Palliative Care Australia has adapted from the World Health Organisation's longer definition of palliative care:

*Palliative care is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goal is quality of life.<sup>20</sup>*

The AHEC Sub Group also notes that there is often a role for palliative care before an individual's condition has become terminal.

For other organisations' definitions of palliative care, please see section 5.2.1.

#### 5.1.2 Paediatric palliative care

In defining transition phases in health and health care including, but not limited to, a transition to palliative care, the AHEC Sub Group recognised that, although the majority of people facing this stage of their life will be adults, it is still applicable to children and young people. It should also be recognised that children and young people may have different palliative care needs to those of adults during this stage. Accordingly the AHEC Sub Group has determined that:

*'Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement'.<sup>21</sup>*

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<sup>20</sup> Palliative Care Australia. 1<sup>st</sup> ed. *Palliative care and end-of-life care: Glossary of terms*. 2008

<sup>21</sup> Association for Children with Life Threatening or Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health. 'A Guide to the Development of Children's Palliative Care Services' London 1997 as cited in the Victorian Paediatric Palliative Care Program 'What is Paediatric Palliative Care?'

### 5.1.3 Palliative care and advance care planning

The transition phase is likely to include considering the development of a palliative care plan and that plan may include developing an advance care directive or similar legal instrument.

Developing these plans can themselves be difficult as it brings to the fore issues such as what is to be a 'good' death, and how the individual concerned prefers to manage this last phase of their life whilst still maintaining a quality of life that they find acceptable. A sense of hope is crucial to this phase of an individual's life

In some cultures it is a taboo to speak about impending death and submissions may identify how those cultures manage the ethical sensitivities which may arise at this time of a person's life.

The AHEC Sub Group has described palliative care planning in terms of advance care planning and for the purposes of this Paper, has taken the definition of advance care planning in the Australian Medical Association's position paper<sup>22</sup>

*'Advance Care Planning' (ACP) [is] a process that allows a competent individual to express their views in relation to future health care decisions when the capacity to express those views is lost, and believes it can play a critical role in reducing the stress to families that participation in health care decisions can cause.'*

The AHEC Sub Group also notes Palliative Care Australia's definition of advance care planning which includes the important concept of values (autarky) and the 'respecting individual choices' program<sup>23</sup>.

*'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. Respecting Patient Choices is one of many programs that supports advance care planning.'*<sup>24</sup>

### 5.1.4 Chronic conditions in Australia

Chronic conditions constitute a large proportion of disease and injury in Australia<sup>25</sup>, and a large proportion of these conditions may be responsive to either prevention or management strategies. Given that a large number of chronic conditions may be self managed, the current focus in Australia is to increase programmes and strategies to assist individuals to self assess and manage their conditions.

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<sup>22</sup> Australian Medical Association. *The role of the medical practitioner in advance care planning*. 2006, accessed from <http://www.ama.com.au/node/2428>

<sup>23</sup> Respecting individual choices: An advance care planning program. <http://www.respectingindividualchoices.org.au/> Accessed 26 March 2009

<sup>24</sup> Palliative Care Australia. 1<sup>st</sup> ed. *Palliative care and end-of-life care: Glossary of terms*. 2008.

<sup>25</sup> Australian Health Ministers' Conference. *National Chronic Diseases Strategy*. 2005

The AHEC Sub Group notes that the incidence of chronic disease in Aboriginal and Torres Strait Islander populations is particularly high.<sup>26</sup>

Recognising the diversity of the definitions of chronic conditions and the pattern that most of them have of listing specific medically diagnosed conditions, e.g. asthma, cancer etc, the AHEC Sub Group has consolidated comments from the targeted consultation process with elements of definitions used by Medicare Benefits Schedule, Palliative Care Australia and the Tasmanian Department of Health.

### 5.1.5 End of life

‘That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.’<sup>27</sup>

### 5.1.6 End of life care

‘End of life care combines the broad set of health and community services that care for the population at the end of their life.

Quality end of life care is realised when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists and support care providers and the community- working together to meet the needs of people requiring care.’ (op cit)

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<sup>26</sup> Australian Institute of Health and Welfare, 2006. “Aboriginal and Torres Strait Islander Health Performance Framework 2006 Report” *Australian Institute of Health and Welfare*, accessed 31/03/2008 from: <http://www.aihw.gov.au/publications/ihw/atsihpf06r/atsihpf06r-c00.pdf>

<sup>27</sup> Palliative Care Australia *Palliative and End-of-life Care Glossary of Terms 2008*, accessed 13/7/09 from: <http://www.palliativecare.org.au/Portals/46/resources/PCA%20Glossary%20Final%20July%202008%20LR.PDF>

## 5.2 Sources that have informed the development and definitions of key terms

In considering this transition phase the AHEC Sub Group has drawn on:

- national and international guidelines around palliative care
- national and international guidelines around end-of-life
- related State and Territory legislative requirements
- individuals with a chronic condition including those from special needs groups
- specific ethical considerations that may arise in older age
- ethical issues for carers of those with a chronic condition
- ethical issues for health care professionals in relation to palliative care and care of individuals as they age.

### 5.2.1 Palliative Care

#### i) World Health Organisation definition of palliative care

'Palliative care is an approach that improves the quality of life of individuals 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, psychological and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of individual care;
- Offers a support system to help individuals live as actively as possible until death;
- Offers a support system to help the family cope during the individual's illness and in their own bereavement;
- Uses a team approach to address the needs of individuals, including bereavement counselling, if indicated;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.'<sup>28</sup>

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<sup>28</sup> WHO Definition of Palliative Care, accessed 13/07/2009 from:  
<http://www.who.int/cancer/palliative/definition/en/>

## ii) World Health Organisation definition of paediatric palliative care

- Palliative care for children is the active total care of the child's body, mind, spirit and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives a treatment directed to the disease.
- Health providers must evaluate and alleviate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

## 5.2.2 Chronic Conditions

### i) Australian Bureau of Statistics

The Australian Bureau of Statistics defines a chronic condition as '... a condition which has lasted, or is expected to last, six months or more.'<sup>29</sup>

### ii) Australian Institute of Health and Welfare

For the purposes of grouping and evaluation of chronic illness and associated risk factors, the Australian Institute of Health and Welfare (AIHW) defines chronic condition as:

'...those involving a long course in their development or their symptoms. They are a major health problem in all developed countries, accounting for a high proportion of deaths, disability and illness. Yet many of these diseases are preventable, or their onset can be delayed, by relatively simple measures.'<sup>30</sup>

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<sup>29</sup> Australian Bureau of Statistics, *Chronic Conditions and Disability, Year Book Australia*  
<http://www.abs.gov.au/Ausstats/abs@.nsf/7d12b0f6763c78caca257061001cc588/4B4499E66C702262CA2572360002BF7F?opendocument> Accessed 19<sup>th</sup> February, 2009

<sup>30</sup> Australian Institute of Health and Welfare, *Chronic Diseases and Associated Risk Factors*,  
<http://www.aihw.gov.au/cdarf/index.cfm> accessed: 21/01/2009

### iii) Chronic Illness Alliance

The Chronic Illness Alliance produced the document *Developing a shared definition of chronic illness*. This document was not able to reach a conclusion on a definition of chronic illness but noted that it includes the following elements:

- ongoing and problematic to the individual concerned;
- affects quality of life and involves making life-style changes such as stopping work;
- impacts on other relationships e.g. family and employment;
- life-long and involves substantial commitment by carer;
- may fluctuate, be episodic and progressive;
- contains elements of uncertainty e.g. future needs, recurrence;
- expensive;
- requires ongoing and complex management including medical, personal care, community support, self-management programs;
- social implications of the diagnosis: e.g frequency of visits, costs, treatments;
- life threatening;
- complex; and
- should include a 'health promoting' ideal.<sup>31</sup>

### iv) Medicare Benefits Schedule- Item 721

'A 'chronic medical condition' is one that has been or is likely to be present for at least six months, including but not limited to asthma, cancer, cardiovascular illness, diabetes mellitus, musculoskeletal conditions and stroke.'

### v) Palliative Care Australia

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 an extended period of time.

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<sup>31</sup> Chronic Illness Alliance, 2002, "Developing a shared definition of chronic illness: The implications and benefits for general practice", *Chronic Illness Alliance*

## vi) Department of Health and Human Services Tasmania

“Chronic conditions are illnesses (both physical and psychosocial), injuries and social problems that are prolonged and cause significant functional impairment, disability or disadvantage. They are usually characterised by complex causality, multiple risk factors, long latency periods, prolonged courses or illness, functional and social impairment, and / or disability.”<sup>32</sup>

### 5.2.3 Advance care planning

#### i) New South Wales

The NSW Department of Health, Health and Research Ethics Branch, has published *Using Advanced Care Directives*. The aim of this guideline is to assist those who need to ‘prepare for likely scenarios near the end-of-life and usually includes assessment of, and dialogue about a person’s understanding of their medical history and condition, values, preferences and personal and family resources.’<sup>33</sup>

#### ii) Victoria

The Victorian Office of the Public Advocate has produced a guidance document entitled ‘Refusal of Medical Treatment’. This guidance interprets the *Medical Treatment Act 1988* for the reader assisting them to understand what the ‘certificate’ does and does not allow and how to ensure the certificate is composed in accordance with the Act.<sup>34</sup>

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<sup>32</sup> Department of Health and Human Services Tasmania, “Strengthening the Prevention and Management of Chronic Conditions”, *Policy Framework 2005, DHHS*

<sup>33</sup> NSW Department of Health, Health and Research Ethics Branch *Using Advanced Care Directives*. 2003. [http://www.health.nsw.gov.au/policies/gl/2005/pdf/GL2005\\_056.pdf](http://www.health.nsw.gov.au/policies/gl/2005/pdf/GL2005_056.pdf) accessed: 03/03/2008

<sup>34</sup> Office of the Public Advocate Victoria ‘Refusal of Medical Treatment fact sheet’, *Office of the Public Advocate*. Accessed 18/03/2009 from: <http://www.publicadvocate.vic.gov.au/media/docs/Fact-Sheet-refusal-of-medical-treatment-fee745e-cfdd-41fc-a71a-80b96f976667.pdf>

## 5.2.4 National Transition Care Program

This program is designed to improve older people's independence and confidence after a hospital stay and to help those older people leaving hospital to return home rather than prematurely enter residential care. It provides short term support and active management for older people at the interface of the acute / sub acute and aged care sectors as well as allowing older individuals and their carers' time to consider longer term care options. It may be a part of the care for a person with a chronic condition entering the transition phase but it is not the subject of this Paper.

Further information about the program is available at:

<http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-policy-transition.htm-copy2>

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## 7. Appendix A: Ethics and the Australian Health Ethics Committee (AHEC)

The statutory functions of AHEC include providing advice, or preparing guidelines, about ethical issues in health. The *NHMRC 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.

AHEC regards ethics as a form of rational inquiry that concerns how we should live and what we should do. Ethics is sometimes said to be merely a matter of individual preference or cultural convention. Although ethical judgements may express personal preferences and may be connected in complicated ways with cultural conventions, some ethical issues will be matters of debate: people of goodwill can reason about them but still reach differing practical conclusions.

Even the best way of reasoning about ethical issues is a matter of debate. For example, some people may emphasise that some acts are morally undesirable in and of themselves, (such as deliberate deception), or may emphasise the inherent moral desirability of certain standards of conduct, (such as integrity in one's relationships with others). Others emphasise the moral significance of anticipating the likely consequences of proposed acts (for example, the likely consequences for a woman who gestates a child for another woman).

Similarly, some people emphasise the duties we owe to each other, for example, the duty to respect another's personal autonomy. Others emphasise the moral claims we are entitled to make against each other, for example, a child's moral entitlement to knowledge of his or her genetic parents.

All of these kinds of considerations matter, even if there can be reasonable disagreement among people about how they are to be balanced.

## 8. Appendix B: Members of the AHEC Sub Group

Reverend Dr Gerald Gleeson (Chair)      Australian Health Ethics Committee  
Member 2006 – 2009 Triennium

Professor Colin Thomson      Chair of Australian Health Ethics  
Committee 2006 – 2009 Triennium

Professor Margaret O'Connor AM      Australian Health Ethics Committee  
Member 2006 – 2009 Triennium

A/Professor Terry Dunbar      Australian Health Ethics Committee  
Member 2006 – 2009 Triennium

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