

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

21 December, 2009

Dear Sir/Madam,

Re: *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.*

We congratulate the NHMRC on producing this discussion paper and the importance that is being given to ethical issues for people as they prepare for end of life decisions. In broad terms we support the principles in this discussion paper but would like to offer the following comments.

General comments

- **Mutual dependence** – a principle that we would like to see emphasized is that of our dependence on each other. We do not see dependence as “a terrible, degrading inhuman reality. It’s part of the design. It is an integral part of the narrative of a person’s life...The human person is the place where freedom and utter dependence are united”¹. In saying this, we do not want to suggest that autonomy is unimportant, but rather to dispel the notion that we are ever completely independent. The act of caring for another is not demeaning but rather it is honoring to that person and at several different points in the life cycle we will all be either in need of care or take on the role of the caregiver.

¹ Professor John Wyatt, 2009 New College Lectures -
<http://www.newcollege.unsw.edu.au/newcollegelectures.html>

- **Humans are spiritual as well as physical beings.** Both aspects of our being are important, but spirituality is particularly important at the end of life. It is our beliefs that profoundly influence our ethical standards and decisions, particularly when confronting death.
- **Good communication** is an essential part of the care given during the transition to palliation and end of life. Many health care professionals have not had the necessary training to comfortably have the kind of conversations that are required during the transition phase of care. We note the Medical Journal of Australia has produced guidelines but suggest that many practitioners have not accessed them².
- **Clarity about treatment goals** is important at every stage of the disease process and will lay important groundwork for a smooth transition to palliation and end of life care. We also suggest that normalising the use of advance directives has the twin benefit of raising these important issues for discussion at an early stage of transition as well as giving patients a sense of control during a difficult time in their lives. It is important that the development of advance directives is done carefully so that they cannot be misused. We would also think that a medical practitioner should be involved in these discussions to make sure that all parties are well informed.

Specific comments

3. Ethical priorities in times of transition in health care

The AHEC sub group suggests that special attention to certain ethical priorities is the key to good decision making (p.17). We would like to suggest that the list should also include:

The value of all human life. We note that the principle of valuing human life underpins point 3.1 about respecting others (page 18) but we believe it warrants separate emphasis. There are conceivably situations where an individual has neither autonomy or autarky but nevertheless their life is still of value, for example someone in a state of post-coma unresponsiveness.

3.1.1 Questions about Autonomy and Dignity for Consultation feedback

Questions c) and d) – these are questions of an existential and spiritual nature, so it is important that spiritual support is available in the health system, for example chaplains, to assist individuals as they consider these types of questions.

² Clayton, J.M., Hancock, K.M., Butow, P.N. Tattersall, M.H.N., & Curnow, 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.

3.2 The Standards and Goals of Health Care

Evaluating risks, burdens and benefits – we agree that making decisions about the benefit of an intervention will involve some consideration of the ‘burden or cost of the treatment and the availability of resources for the family and/or the community’. However we suggest that this should in no way place pressure on patients to accept an inferior therapeutic intervention or discriminate against people from economically disadvantaged backgrounds.

3.2.1 Questions about Standards and Goals of Health Care

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?”

We suggest that the word ‘best’ is an emotionally charged word that can create feelings of guilt for carers who often feel that it is their responsibility to take on the role of full time carer, regardless of their capacity to do so. The word ‘best’ also implies ‘only’ –that any other kind of care arrangement would be inferior. Can we suggest an alternative way of asking the question might be “Am I able to provide care for this individual? If not, what are the options? (eg: more support at home, respite or full time care in a facility)”.

g) “When should the goal and scope of treatment options.....” We suggest that rather than beginning the question with ‘when’ it ought to ask ‘how do I determine when.....’ Perhaps questions a) to d) ought to be considered by the health professionals as well.

3.3.1 Questions about acting in the best interests of the individual

a) “Have I expressed my wishes clearly?” should also include “and am I confident my wishes have been heard and understood?”

3.4.1 Questions about justice, especially in regard to resource allocation

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?”

We do not think that these two questions are appropriate. It is natural that people facing transition will contemplate whether they are a burden to their carers but we think that those kinds of reflections ought to come from the individual concerned in their own time and not be prompted by seemingly loaded questions. Perhaps another way of opening up such a discussion could be by asking “how do I think my family/carers feel about their role as a carer? Have I discussed this with them?”

Question b) raises an important issue that undoubtedly needs discussion but we do not think it ought to be put to an individual in this way as it might be interpreted as placing undue pressure or responsibility on them to solve issues for other people. We think that health professionals need to empower carers to relinquish their role as primary carer when

the time is right, rather than making this the responsibility of the individual receiving the care. The earlier these kinds of discussions occur, to anticipate what may lie ahead, the smoother the transition.

We wonder whether these kinds of questions belong in a section on Justice as they could be interpreted as implying there is something fundamentally unjust about having to care for someone or be cared for. As we indicated in our general comments, we think that being dependent on others should be normalized and not seen in pejorative terms of being a 'burden'. Perhaps the questions would be more appropriate under the heading 'Support'.

We recognise that issues of fairness will inevitably come up for people with a terminal condition and these are very deep questions that need to be handled sensitively. But we are unconvinced that it is helpful to ask these particular kinds of leading questions a) and b) to people facing transition.

Sample questions for health care professionals - We fully support a discussion about 'Justice' but feel it is most appropriate for the health professionals and the wider community. A further question following e) and f) could be "What kind of resource allocation is needed to improve or maintain the quality of care for those in transition to palliation and end of life?" For example, resources need to be allocated to improved communication if it is to be done well. General Practitioners need to be given a Medicare item number for discussions about palliative care and end of life decisions, particularly for rural GPs who are often the only ones providing palliative care.

We thank you once again for the opportunity to comment on this discussion paper and hope that the feedback you receive will assist you in your task of preparing resources for people facing transition and their carers.

Yours sincerely,

Dr Megan Best
On behalf of
The Social Issues Executive
Anglican Church Diocese of Sydney