



The Patient's Choice: Quality at the End of Life Learning Guide





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About the Rural Health Education Foundation

Originally established in 1992, the Rural Health Education Foundation provides independent accredited education services to General Practitioners and other health professionals, working in rural and remote Australia.

Health education via satellite, the internet and DVD

The Foundation produces and broadcasts distance education programs using digital satellite technology, the internet, DVDs and other television services. The Foundation operates a growing network of more than 660 receiving sites, called the Rural Health Satellite Network.

Today, the Foundation's satellite network is one of the largest dedicated networks of its kind in the world, available to more than 90 per cent of rural doctors and other health professionals.

A non-profit lifeline to the bush

The Rural Health Education Foundation is a non-government, not-for-profit organisation that provides an education and information lifeline to rural and remote health professionals.

The latest topics via the latest technology

The satellite and internet technology ensures that health professionals gain access to continuing education, without needing to find locum support or leave their communities.

The Foundation's programs are broadcast and distributed in Australia a number of times each month to meet the professional development needs of all disciplines. They explore major health issues and provide information on the latest and best health and community care practices. They also address the prevention and current management of common health problems.

Presented by experts

The programs feature leading medical and health professionals in a panel discussion. The panels usually include a rural health professional and allow for participation from the viewing audience across Australia.

The Patient's Choice: Quality at the End of Life

Learning Guide

The Learning Guide draws on and seeks to integrate all the elements on the DVD, which include

1. A Rural Health Education Foundation program, entitled *End of Life Care*, first broadcast in 2009, and repeated in 2010
2. A filmed interview with Dr Bill Silvester, Director of the *Respecting Patient Choices* Program
3. A filmed segment on *Advance Care Planning*
4. A variety of resource material that has been embedded on the DVD

The Learning Guide should be used in whatever way best supports your professional needs or those of your group. A wide range of activities is included which you can adapt to your professional development requirements or to your particular professional needs.

A [Guide to Facilitating Adult Learning](#) booklet has also been developed by the Foundation to support the facilitation of discussion with small groups. It covers the basic aspects of how people think and learn, running groups and facilitating learning in face-to-face settings. It is designed to provide some basic instructional information to assist people facilitating face to face learning. The Guide can be found on the Foundation's website at www.rhef.com.au

Learning Objectives

After working through the Learning Guide, participants will be able to:

- Identify the issues and concerns for patients and their families at end of life
- Effectively communicate aspects of end of life treatment and care to patients and families
- Understand the purpose and principles of *advance care planning*
- Describe the role of the multidisciplinary team in providing end of life care

End of Life Care: The Original Program

The original program – *End of Life Care* – was broadcast by the Rural Health Education Foundation in 2009, with funding from the Department of Health and Ageing. It proved to be one of the most popular programs the Foundation has produced, and it was broadcast again in 2010.

Below you will find a short description of that program:

Each year half a million Australians experience the impact of terminal illness and the capacity of our health services to respond is often limited. Appropriate end of life care, treatment and communication are vital skills for all health professionals.

Increasingly, patients with terminal illness are expressing the wish, if possible, to be cared for and to die at home. This need is of particular importance to those living in rural or remote areas who would otherwise experience isolation and distress if they were moved to metropolitan centres for their end stage care. Indigenous people, especially in rural and remote areas, consistently express the wish to die at home, connected to land and family.

This program explores the issues involved in end of life care. It looks at the need for people approaching the end of life to have accurate information and a specific assessment of their needs. It examines the latest developments in palliative and end of life care, and discusses some of the ethical issues involved.

The New Program

In response to the widespread interest, the Department of Health and Ageing has provided extra funding for a new program, incorporating *End of Life Care*, and adding a variety of resources to it, including this Learning Guide. The intention is to provide a more comprehensive learning experience and to extend access to a broader range of health professionals and facilities.

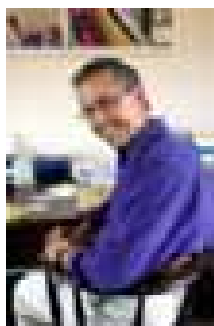
The new DVD includes detailed information, through the use of filmed interviews and case studies, on the *Respecting Patient Choices* organisation which offers training in the provision of advance care planning. The latter is central to giving patients the opportunity – in conjunction with family members, carers, and medical staff - to think about and make choices regarding their palliative and end of life care.

The DVD also includes a wide range of resource material which can be printed and used to support good practice in end of life care.

Please Note

The chapters in the Learning Guide do not correspond with the chapters you will find when you view the original program.

End of Life Care Program Presenters



Chair: Dr Norman Swan (Panel Chair)

Dr Norman Swan regularly presents Rural Health Education Foundation satellite broadcasts. He is best-known for his wide broadcasting experience, including the award-winning *Health Report*, which he produces and presents for ABC Radio National, as well as his other ABC Radio and Television program hosting. Dr Swan trained in Medicine in Scotland and in Paediatrics in London and Sydney. A broadcaster and journalist with the ABC's Science Unit since 1982, he has been Australian Producer of the Year and was awarded a Gold Citation in the United Nations Media Peace Prizes.



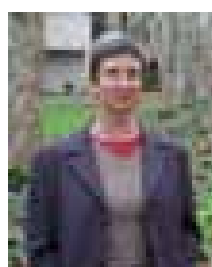
Professor David Currow – Professor David Currow holds the Chair of Palliative & Supportive Services at Flinders University, Adelaide. He is a Senior Associate Editor of the *Journal of Palliative Medicine* and a member of the www.caresearch.com.au team. David holds competitive research grants from the National Health & Medical Research Council and the National Institutes of Health



Ms Nikki Johnston (Fursdon) - Nikki began nursing nearly 20 years ago. Her early experience working in Bone Marrow Transplant, Haematology and Oncology gradually led her towards palliative care. She is now a Palliative Care Nurse Practitioner at Canberra Hospital. She is an inaugural member of Palliative Care Nurses Australia as well as a member of the Australian College of Nurse Practitioners. She had a teaching role with the Respecting Patient Choices Programme in the ACT. With the support of a Palliative Care Foundation Scholarship, Nikki has undertaken the Master of Nurse Practitioner degree in Palliative Care, at the University of Newcastle.



Dr Joel Rhee - Dr Joel Rhee is a General Practitioner and a conjoint Lecturer at the University of NSW. He is also a NHMRC PhD scholar with the Centre for Primary Health Care and Equity at the School of Public Health and Community Medicine at the University of NSW. His research study is on the topic of “Advance Care Planning in the Primary Care Context”. He has also conducted research into the delivery of Palliative Care by General Practitioners and has a clinical interest in aged care and general practice palliative care. Dr Rhee also has rural experience, having worked as a registrar in Moree NSW.



Professor Wendy Rogers - Wendy started her professional life in medicine, specialising in general practice after graduating from the Flinders University School of Medicine. Following a period in general practice and occupational health, Wendy went back to Flinders where she completed her PhD, looking at ethical issues in general practice. This work focused on trust in the doctor-patient relationship, and formed the foundation of her co-authored text *Practical Ethics for General Practice*. In 2004, Wendy took up the position of Associate Professor of Medical Ethics and Health Law at Flinders university, and in 2009 she went to Macquarie University with a joint appointment in the Philosophy Department and the Australian School of Advanced Medicine. She has published extensively in medical and bioethics journals.

Chapter 1

Chapter 1: Introduction

A recent article by Australian authors in the BMJ (Detering et al 2010) states that

there has been an increasing awareness of the inadequacy of end of life care and of the poor knowledge of patients' wishes about their medical treatment at a time when they lose the capacity to make decisions, resulting in patients being cared for in a way they would not have chosen.

Activity 1

- (i) Discuss this assessment. Why do you think there is such poor knowledge of patients' wishes about end-of-life medical care?
- (ii) Think of a patient in your own practice who has been cared for at the end of their life in a way that he or she would not have chosen. What contributed to this outcome?
- (iii) Think of a patient currently in your care who has a terminal illness. Do you know what his/her wishes would be? How openly have these issues been discussed with the patient?
- (iv) How would you rate your own capacity in such discussions?
- (v) Identify areas of your practice that you would aim to improve in order to better address these issues with patients.

Chapter 2

Chapter 2: Palliative Care, End of Life Care and Advance Care Planning

From the Panel Discussion

- Norman Swan notes that there are a variety of terms that are relevant to the discussion, none of them easily defined.
- Prof David Currow goes on to define *palliative care* as occurring when a patient has a predictable life-limiting illness, and is supported through that by a team of people, including family, care-givers, and health professionals.
- Prof Currow distinguishes *end of life care* as a subset of *palliative care*, focusing on the last few days or hours of life.
- Nikki Johnston describes *advance care planning* as essentially a form of patient-centred care that helps patients to reflect on what is important to them, on their beliefs, values, goals and preferences in life, and leading to an agreement – ideally reached with their families as well as their health providers - about how patients want to be cared for if they reach a point where they can no longer communicate their wishes about medical care.

Activity 2

- (i) Is there anything you would add to these ‘definitions’?
- (ii) As the panel discussion makes clear, *advance care planning* is something that can occur at the point of diagnosis, as a terminal phase of illness approaches, or as a routine part of normal health care. Discuss these options.
- (iii) Advance care planning is increasingly seen as central to good palliative and end of life care. Consult the Respecting Patient Choices website which discusses an Australian model for advance care planning and provides a range of resources for both patients and health professionals. <http://www.respectingpatientchoices.org.au/>
- (iv) As is noted on the program, there are different legislations for *advance care planning* in each state and territory in Australia. Click on the tab for “State Specific Information” on the top of the *Respecting Patient Choices* website.

National Palliative Care Strategy

The National Palliative Care Strategy¹ is the policy document that the Australian Government and State and Territory governments use to guide palliative care policy development and service delivery across Australia. In the release of the recently-updated Strategy (2010), it was noted that “each year (in Australia) more than 20,000 people receive specialist palliative care and more than 500,000 patients, carers, family members or friends are affected”.

The Strategy has adopted the World Health Organisation definition of *palliative care*.

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- 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.²

¹[http://www.health.gov.au/internet/main/publishing.nsf/Content/533C02453771A951CA256F190013683B/\\$File/PalliativeCareStrategy.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/533C02453771A951CA256F190013683B/$File/PalliativeCareStrategy.pdf)

²www.who.int/cancer/palliative/definition/en/

Activity 3

- (i) Approximately how many of your patients are currently receiving palliative care?
- (ii) On the basis of the quoted numbers above, how many people, in addition to your patients, would you estimate are affected?
- (iii) How able is your practice to address the broad range of palliative care interventions contained in the WHO definition?

The Role of the GP

Caring for people nearing the end of their lives is part of the core business of General Practice.

Royal College of General Practitioners EOLC Strategy (2009)

Talking about death and dying with patients is one of the most difficult discussions GPs will face, and requires considerable sensitivity and skill. And yet it is incumbent on us as professionals to support patients in this way, in honest yet compassionate (conversation), developing both realistic hope and internal resilience, and guiding people towards making the best choices for them.

Royal College of General Practitioners EOLC Strategy (2009)

- Norman Swan notes in the program that most palliative care is actually carried out by GPs.
- Given an ageing Australian population, and rapid developments in medical care, the number of patients living with cancer, end stage chronic disease, and increasing frailty will increase, and these patients make up a large section of the GP's caseload. By default, GPs will increasingly be concerned with, and central to, palliative and end of life care for many patients in the community.
- The literature suggests, however, that training in such care has been patchy for many GPs. A recent article in *Australian Family Physician* (Sanderson and Tieman 2010) noted, moreover, that while many GPs are actively involved in providing palliative care, a considerable number are not. One study reported that 25% of GPs in metropolitan Sydney do not offer such care, respondents giving a number of reasons including lack of specialist knowledge, time constraints, and discomfort with the complex psycho-social needs of dying patients. The article stresses the need for ongoing education and support for GPs to provide palliative care.

- In 2006, Prof Geoffrey Mitchell, who is also a GP, wrote that “About a quarter of GPs will not take palliative patients on. The reasons are not known; but are probably discomfort at dealing with symptom control – especially with a specialist service in the area; concern at doing house calls, competing priorities such as family commitments, personal comfort in dealing with dying patients, and changing out of hours arrangements and expectations”.
- Research published in Australian Family Physician noted that, contrary to patient report, “Many GPs believe that patients are not able to face discussion around death and dying” (Burgess, Brooksbank and Beilby, 2004)
- Research indicates that GPs most comfortable dealing with palliative patients are those who have been in practice for some time (Mitchell, G., 2006)

Activity 4

- (i) Do you agree that providing high-quality care at the end of life is “core business” for GPs?
- (ii) Dr Craig Brown notes that “doctors are hard-wired to save lives”. What are the consequences for discussions with patients about dying, and for the shift from aggressive medical care to a more palliative approach?
- (iii) Dr Bill Silvester notes that patients wait for their doctors to raise issues of palliative and end of life care. Does this accord with your experience? What do you think is the reason?
- (iv) Identify the main aspects involved in helping “*guide patients to making good choices*” about treatment options at the end of life?
- (v) Yvonne Luxford comments that every health professional will encounter patients in palliative and end of life care at some point in their professional life. Why do you think experience makes a difference to an interest in undertaking this sort of care? How would you encourage a recent medical graduate to think more about this aspect of general practice?
- (vi) Some GPs and health care professionals express concern that refusal or withholding of medical intervention is akin to euthanasia. What is your opinion of this?



An editorial in a recent MJA issue contains the following:

Palliative care and aged care should not primarily be the province of the hospital and the acute health care system, and our continued acceptance of this and of the concentration of health care spending in the last months of life is no longer tenable. It represents both bad care and a waste of money.

See the online edition (23rd May, 2011) of the editorial and several pertinent research articles on palliative care <http://www.mja.com.au/>

Activity 5

(i) Consult the National Palliative Care Strategy referred to earlier

([http://www.health.gov.au/internet/main/publishing.nsf/Content/533C02453771A951CA256F190013683B/\\$File/PalliativeCareStrategy.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/533C02453771A951CA256F190013683B/$File/PalliativeCareStrategy.pdf))

(ii) Note the following quote from the Strategy:

Most healthy Australians, when asked where they would prefer to die, nominate their home as their preference. However, the statistics on place of death indicate that this is relatively uncommon — only 16% of people die at home. Twenty per cent of people die in hospices and 10% in nursing homes. The rest die in hospitals. This results in a high cost burden for health systems and potentially a poorer quality of death.

What are the implications for general practitioners?

(iii) What training do you have in the provision of palliative care? Identify the gaps in your knowledge and skill base.

(iv) Do you agree that there is a need for ongoing education and support if GPs are central to providing palliative care?

(v) If so, what would you include in such ongoing education?



Some important resources include:

- The Therapeutic Guidelines for Palliative Care Version 3 is a very helpful resource. You can see what's included by looking at www.tg.org.au/?sectionid=47. This publication normally costs \$39 but clinicians can obtain a free copy from the Australian Government by completing the Palliative Care Publications Order Form (which you will find in the Resources Section on the DVD) and requesting item PC68.
- Another useful resource is the Adult Palliative Care Formulary put out by the Tasmanian Department of Health and Human Services, which you will also find in the Resource section on the DVD.



There are a number of other resources that are useful for ongoing education regarding the provision of palliative and end of life care, many of which are referred to throughout the Learning Guide. You might look at some of the following websites:

www.respectingpatientchoices.org.au

The Respecting Patient Choices website provides information about training, and materials for helping patients think about their preferences for future healthcare, particularly if they were to be in a situation where they might not be able to competently contribute to their end-of-life decisions.

www.caresearch.com.au

CareSearch *palliative care knowledge network* is an online resource consolidating evidence-based and quality information for various groups within the palliative care community. The website has been funded by the Australian Government as part of the National Palliative Care Program.

www.pepaeducation.com

The Program of Experience in the Palliative Approach (PEPA), funded by the Australian Government, has as its aim improving the quality and accessibility of palliative care services to all people with life-limiting conditions and their families. The website has resources for a variety of medical and health professionals, and contains special sections for GPs in rural/remote areas, and for Aboriginal and Torres Strait Islanders Health Workers.

www.palliativecare.gov.au

Palliative Care Australia is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life for all. The organisation offers a number of helpful resources, including one - *Journeys: Palliative care for children and teenagers* - for medical and health professionals who are working with children and their families.

www.agpn.com.au/programs/rural-palliative-care-program

The Australian General Practice Network, with funding from the Australian government, has undertaken the development of a "Resources for a Rural Palliative Care Program". The resource kit has a particular focus on the development of collaborative models of care that will significantly improve rural community access to timely, quality and coordinated palliative care.

www.mja.com.au/Topics/Palliative%20care.html

This web page is a collection of 68 articles on Palliative Care that have been published in the Medical Journal of Australia, and covers a wide variety of clinical and other relevant issues.

www.healthinsite.gov.au

This Australian Government website provides excellent resources for health professionals on many aspects of palliative and end of life care.



Clinical Guidelines

Difficulty in communication between health care professionals and patients regarding prognosis and end of life issues is regularly noted (Gysels et al 2004). Skills in such communication are increasingly recognised as vital for GPs and other health care professionals caring for patients with life-limiting illnesses, and their families.

In 2007, the MJA published a very ‘user-friendly’ set of “*Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers*”. The MJA has generously allowed the guidelines to be embedded on the DVD and you are encouraged to consult them regularly as you work through the Learning Guide. You can also access them at the following address http://www.mja.com.au/public/issues/186_12_180607/cla11246_fm.html

Activity 6

- (i) List the factors that make the discussion about death and dying one of the most difficult that GPs will face with their patients.
- (ii) Identify two areas of difficulty in communication which are familiar to you, and then consult the *Clinical Practice Guidelines* referred to above, especially Box 13 (Discussing the Process of Death and Dying) to see how these issues are addressed there.
- (iii) How important do you think the GP’s own attitudes about death and dying is to his/her ability to provide good palliative and end of life care? Give an example of how particular attitudes may prove problematic.

Activity 7

Prof Currow notes on the program that the palliative care team often consists simply of the GP, the patient’s family and friends, and the community nurse.

- (i) How closely does this accord with your experience?
- (ii) What do you think is the role of “family and friends” in the palliative care team? What are the implications for the GP?
- (iii) Are there other health professionals you might include in a palliative care team?
- (iv) What role would you see for a psychologist, for example?

End of Life Care in Rural Australia

- As is noted in the program, there are extra pressures associated with caring for dying patients in rural and remote Australia, such as limited access to a range of health professionals and resources, and the increasing centralisation of specialist care.
- There was also discussion about the potential benefits of offering palliative care, and advance care planning, in a rural location, including:
 - (a) patients and their families often have long-standing relationships with their GPs and other health professionals;
 - (b) there is corresponding potential for greater continuity of care; and
 - (c) the GP can often continue to coordinate care if the patient is admitted to the local hospital.

Activity 8

- (i) What would you identify as the major difficulties in providing palliative care in rural and remote Australia?
- (ii) What access do you have to specialist palliative care facilities and support, and how closely do you work with them?
- (iii) There is mention on the program of phone contact for advice – do you know how to access this facility?
- (iv) How do you negotiate the interaction between specialist palliative care and local GP/care/family palliative support?
- (v) Do you think conversations about advance care planning and end of life care are easier to initiate if you have known the patient and their family over a long period of time? Can long acquaintance with the family also make it more difficult?
- (vi) Can a team approach facilitate care in rural areas? What professionals would you include?
- (vii) How important do you think continuity of care is in a situation like this?

Activity 9

Consult the Learning Guide for GPs and Rural Medical Staff on the PEPA website <http://www.pepaeducation.com/GPs/>. You can also look at the PEPA video which you will find in the Resource section on the DVD.

The Issue of Prognosis

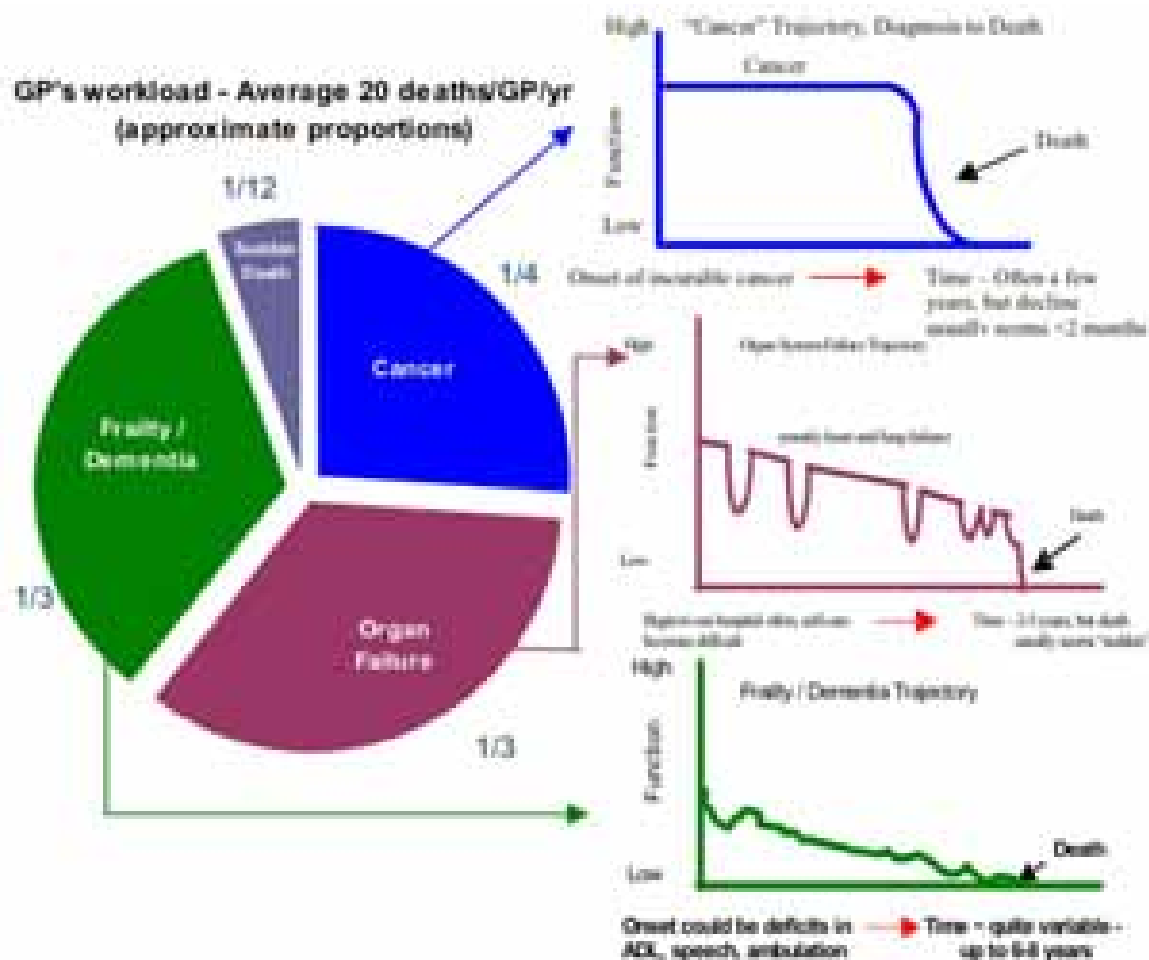
As is noted in the program, the difficulty in predicting disease trajectories is one of the challenges in identifying the point at which palliative and supportive care becomes the appropriate clinical approach. The National Palliative Care Research Program has identified this as a priority research area.⁴

Activity 10

- (i) Do you agree that this difficulty complicates the issue of when to introduce discussions about advance care planning and end of life care? Why does the uncertainty make it more difficult?
- (ii) Give an example of a patient where this was, or is, an issue.

Points from the Panel Discussion

- Nikki Johnston notes that while it is reasonably easy to know when a patient with cancer is approaching the last phase, it is more difficult with chronic illness or dementia. Cancer patients are far more likely to be referred for advance care planning than COPD patients.
- Prof Currow outlines the trajectories of different illness situations, using the following graphic:



⁴ www.nhmrc.gov.au/_files_nhmrc/file/grants/types/granttype/strategic/Palliative-care-phase1-summary.pdf

- Dr Rhee notes that it's precisely the difficulty in predicting a disease trajectory that means it's a good idea to think of advance care planning as a routine part of health care with patients.

Research concurs with panel discussants that patients with COPD receive less advance care planning and palliative care compared with patients with other diseases with similar prognoses. (See, for example, *Current Opinion in Pulmonary Medicine*: March 2011 - Volume 17 - Issue 2 - p 103–109.) Curtis et al (2005) also note that COPD patients are more likely to die in hospitals, on ventilation and with dyspnoea, when they would rather die in comfort; and there is little end of life planning until terminal end of disease.

Activity 11

- (i) Look at Box 4 (How to discuss prognosis and end-of-life issues) in the *Clinical Guidelines* (in the Resource section).
- (ii) Do you agree that it is much easier to address issues of palliative and end of life care with patients who are on the 'blue line'? Think of a patient on one of the other lines with whom you might have difficulty talking about these issues.
- (iii) Different models of care will be appropriate for people with different illness trajectories. Outline some of the differences.
- (iv) If you were caring for a patient with severe chronic obstructive pulmonary disease what issues would you think appropriate to draw the patient's attention to?

Prognosis in non-cancer patients is clearly more difficult. More precise indicators would also enable patients to make more informed decisions about their ongoing medical treatment. Research suggests that prognosis is a significant factor for patients age 65 and over in determining whether or not to accept life-sustaining treatment. Patients were more likely to choose antibiotics, cardiopulmonary resuscitation, surgery, and artificial nutrition/hydration when there was even a slight chance of recovery from a stroke or a coma than when there was no hope of recovery. Straightforward conversation about potential disease trajectories is an important aspect of the transition to palliative and end of life care.

Activity 12

The following article addresses some of these issues. It looks at a series of clinical indicators for indentifying patients who are appropriate for palliative care assessment and for those who are in the last days of life.

- (i) Read "Recognising and managing key transitions in end of life care: Boyd, K., and Murray, S., *BMJ* 2010; 341: Published 16 September 2010
www.bmj.com/content/341/bmj.c4863.long *palliative medicine*
- (ii) Would such an approach be helpful in considering the timing of introducing issues of advance care planning?
- (iii) Look at Box 1 (Timing of Discussion) in the *Clinical Guidelines*.

Activity 13

- (i) Identify a patient with whom you have had, or anticipate having, difficulties discussing prognosis, the transition to palliative care, and the benefits of advance care planning? What are the difficulties and how do you go about confronting them?
- (ii) Think of a patient with whom you would need to be aware of cultural differences and sensitivities when talking about prognosis, the transition to palliative care, end of life care, and issues of death and dying generally? How would this affect your conversation? (See Box 4 of the *Clinical Guidelines*.)
- (iii) Prof Currow also highlights the reality that some families wish to protect their loved one from information about their diagnosis and illness trajectory. Why in your experience do families not want their relatives told?
- (iv) How do you go about negotiating this issue? Are there circumstances in which you would comply with the family's wishes?
- (v) What do you think are the significant ethical issues in this situation?
- (vi) Consult Boxes 14, 15 and 16 of the *Clinical Guidelines* (focussing on some difficult scenarios) for some useful intervention suggestions.

Chapter 3

Chapter 3: Advance Care Planning

Enabling patients to choose how they would like to be cared for near life's end is important because: 85 per cent of patients die after a chronic illness; 50 per cent are not in a position to make a decision about treatment near the end of life; patients' relatives frequently don't know what their loved ones want; and doctors may provide aggressive treatment for patients who would not want it. Above all, many patients are kept alive in circumstances they would not choose.

<http://www.theaustralian.com.au/news/health-science/when-a-death-wish-is-desirable-end-of-life-decisions/story-e6frg8y6-1225983238944>

According to Detering et al (2010) the elements of advance care planning include:

- Clarifying a patient's understanding of their illness and treatment options
- Understanding their values, beliefs, and goals of care
- Identifying their wishes

Activity 14

- (i) Look at the DVD segments on the importance of *advance care planning*, and the development of the Respecting Patient Choices program (www.respectingpatientchoices.org.au)
- (ii) You can use the interview with Dr Bill Silvester, who is Director of Respecting Patient Choices, as a mini 'professional development' program for your health professional group. He addresses a number of questions (each appearing on the screen as a graphic) which can be used to prompt discussion.

According to a document on Advance Care Planning put out by NSW Health (www.archi.net.au/documents/e-library/models/acp/advance-planning.pdf), as a result of an Advance Care Planning discussion

- People know they have choices.
- There is a clear understanding and agreement regarding a person's values, goals and preferences for end-of-life care.
- The person responsible in the event of incapacity is clarified
- The appointment of an enduring guardian is facilitated
- A multi-disciplinary approach is instituted
- Staff develop relevant skills and knowledge
- Systems and process are in place to ensure everyone is aware and follows the individual's wishes.

Effectiveness of Advance Care Planning

(i) The NSW Health document further reports that international research has shown the following consequences of good advance care planning:

- Earlier recognition of poor prognosis
- Agreement on goals of care
- Less ineffective ICU treatment
- Improvement in patient insight
- Reduced length of hospital stay
- Reduced ICU mortality
- Increased dying at home (in place)
- Greater understanding between patients and their carers
- High acceptability of the process
- Increased communication
- Fewer hospitalisations of patients in residential aged care facilities
- Increased discussion of prognosis with doctors
- Positive attitudinal and affective outcomes for patients

(ii) Local studies, such as that of Caplan et al (2006) in Sydney, show similar results (<http://www.ncbi.nlm.nih.gov/pubmed/16807309>). In their study of advance care planning with patients in Residential Aged Care Facilities, the authors reported:

- 20% fewer acute hospital admissions from patients with advance care plans
- no increased mortality associated with staying in the RACF compared with transfer to acute care
- 90% patients wanted to die in place and 88% of residents with plans in place did so
- 70% of residents without plans died in acute care hospitals

(iii) In another study, recently published in the British Medical Journal, clinicians from the Austin Hospital reported that, of a number of elderly patients who had died, end of life wishes were known and respected in 86% of patients who were offered advance care planning, compared with only 8% of a control group (<http://www.bmj.com/content/340/bmj.c1345.full>).

Significantly, the study reported several secondary outcome results:

- patient satisfaction with the process of their medical care was much higher in the intervention group
- family members of patients who had died in the intervention group had fewer symptoms of post-traumatic stress, depression and anxiety
- family members of the intervention group were more likely than those of the control group to be very satisfied with the quality of death, from both their own perspective and the perceived perspective of the patient.

Despite this international and local research demonstrating the effectiveness of advance care planning, there continues to be low uptake of the use and implementation of Advance Care Plans (Seal 2007). As a result, life-sustaining measures, such as CPR, are routinely used.

In addition

- there continues to be large numbers of patients dying in hospital when their preference would be to die at home (as is reported in the National Palliative Care Strategy);
- there is ongoing poor cost effectiveness of hospital interventions (it is estimated that 20 to 30 percent of these medical expenditures may have had no meaningful impact).

Why the low up-take?

There are a number of suggestions.

- (i) Detering et al (2010) suggest several potential barriers:
 - a) Lack of availability of trained staff with the time, competence, and confidence to discuss advance care planning with patients
 - b) Lack of organisational commitment and policy to support advance care planning
 - c) Lack of understanding and support for the process on the part of hospital and aged care facility health and medical staff
- (ii) NSW Health (www.archi.net.au/documents/e-library/models/acp/advance-planning.pdf) suggests that many health professionals believe that they already know what their patients would want in the event of their being unable to communicate their wishes. According to NSW Health, however, *there is clear evidence that they don't*.

Activity 15

- (i) What's your self-assessment in this regard? Do you think you know what your patients would want if they were not able to communicate it to you or other medical caregivers? If so, what do you base your conclusion on?
- (ii) What other factors might contribute to a low uptake of the use and implementation of advance care planning?

The NSW Health document identifies the following items as underpinning a general reluctance to have a clear and agreed understanding regarding a patient's wishes:

- The complexity involved in decision making.
- Anxiety related to death.
- Denial.
- Lack of time dedicated to understanding principles.
- Inability of patients, health care providers and other professionals to identify a substitute decision maker or a 'person responsible'.

- Lack of trust in the process and general confusion about the term advance care planning. Care teams having a poor level of knowledge and skills.
- Reluctance of health care professionals to discuss or initiate conversations about Advance Care Planning or to discuss end of life issues.
- Difficulty of interpreting plans in the 'real world'.
- Patients fear that they may not be able to change their mind.

Activity 16

Which of these factors are most relevant for you?

Who is Responsible for Advance Care Planning?

- The role of the GP in ascertaining in good time a patient's wishes regarding treatment options in end of life care is still a matter of debate. Some GPs believe that their role is central. Others suggest that, while discussions of palliative care are very much the GP's role, advance care planning – which often involves lengthy discussion both with the patient and the patient's family – is a process that the GP should support rather than direct.
- Emotional support for the patient and their family, for example, is often a valuable component of advance care planning, as people struggle to come to grips with the consequences of severe illness, and the likelihood of death. Such a role is often better undertaken by a nurse who knows the patient and family well, or another allied health professional such as a social worker.

Activity 17

- (i) Watch Nikki Johnston's interview with Adele at the end of the segment on *advance care planning*. Clearly such a discussion is not just the act of completing a form. Identify the skills you think would be required to conduct such a discussion.
- (ii) Compare your list with the following suggestions from NSW Health.
 - Interpersonal and communication skills
 - Knowledge of conditions, treatment, medical knowledge to explain common terms
 - Knowledge of consent, legal and ethical issues
 - Cultural and religious competence and awareness
 - Comfortable talking about end of life choices
- (iii) What do you think the value of this interview is to Adele?
- (iv) How useful do you think it is to have a 'support person' for someone in Adele's position?
- (v) Read Box 11 (Advance Care Planning) in the *Clinical Guidelines*.

Activity 18

- (i) Download an Advance Care Planning document from the *Respecting Patient Choices website* and undertake an advance care planning discussion with a colleague.
- (ii) Discuss the experience and identify points of uncertainty or difficulty.
- (iii) Look at the Key Recommendations (and accompanying discussion) in the *Clinical Guidelines*, conveyed by the acronym PREPARED:

Prepare for the discussion

Relate to the person

Elicit patient and caregiver preferences

Provide information

Acknowledge emotions and concerns

Realistic hope

Encourage questions and further discussions

Document

- (iii) Nikki Johnston mentions on the program that she has her own Advance Care Plan. Do you? Does the program make you more inclined to fill one out?
- (iv) Emma Awizen talks in the *Advance Care Planning* segment on the DVD about the importance of training people to undertake the sort of discussion you have just been through. What aspects would you identify as benefiting from specific training?

Respecting Patient Choices training



As Emma mentions, the Respecting Patient Choices organisation offers an e-learning course on Advance Care Planning. This course is Part 1 of the course, and it is geared to provide a broad introduction to ACP. It covers basic definitions, legal aspects, considerations regarding end of life decision-making and communication, the actual process of holding advance care planning conversations, as well as systemic matters that underpin ACP.

There is a Part 2 which you can also do. It is a full day workshop that focuses on communication skills, giving you the opportunity to train and build on your advance care planning skills in an applied setting. See the website at <http://www.rpctraining.com.au/index.php>

Activity 19

There is much mention on the program of the benefits of advance care planning being considered a routine part of medical care. What do you think of this idea? How would you consider introducing the topic to a patient who is not affected by any life limiting illness?

Activity 20

- (i) How would you go about discussing the nature and appropriateness of cardiopulmonary resuscitation with a patient?
- (ii) Have a look at Box 12 (“No CPR” orders) in the *Clinical Guidelines*.

Activity 21

- (i) What do you see as the benefits of the GP being the one to have this discussion with a patient and their family?
- (ii) Who else in your practice – eg., a practice nurse – would be in a position to have this conversation?
- (iii) Is it a role for an allied health worker eg., social worker, psychologist? What contribution do they potentially make to the patient's or family's experience of the discussion?
- (iv) Who is in the best position to have such a discussion with patients in Residential Aged Care Facilities?
- (v) See the discussion of advance care planning in different health contexts in the NSWHealth document (www.archi.net.au/documents/e-library/models/acp/advance-planning.pdf) pp.14-17
- (vi) What would you say to a patient who is concerned about filling out an advance care form in case they change their mind? (See the Frequently Asked Medico-legal Questions page on the *Respecting Patient Choices* website at http://www.respectingpatientchoices.org.au/index.php?option=com_content&view=article&id=42:frequently-asked-medico-legal-questions@catid=4:rpc-and-the-health-professional&Itemid=43)

Activity 22

- (i) What would you nominate as the primary ethical principles underlying the process of advance care planning?
- (ii) See the discussion of ethics on the *Respecting Patient choices* website at http://www.respectingpatientchoices.org.au/index.php?option=com_content&view=article&id=27:the-ethics-of-advance-care-planning&catid=3:more-information&Itemid=28

Activity 23

The *Clinical Guidelines* note the following:

If health care professionals are to be encouraged to discuss prognosis and end-of-life issues with people who have advanced life-limiting illnesses, it is important to acknowledge the need for support and self-care of the health care professionals. Such support includes debriefing with colleagues, encouraging the development of strong collaborative team relationships, and providing communication skills training.

- (i) Why do you think this is so?
- (ii) What resources does your practice have for providing such support, and how would you go about increasing those resources?

Chapter 4

Chapter 4: Case Studies

The following case studies are taken from the original program and formed the basis of much of the discussion. Select what you feel is relevant from these two case studies, or substitute patients of your own.

Case Study 1: John

John is a 56 year old man, with a wife and two adult children, who lives in a country town. He has smoked heavily since he was 16, and has had numerous admissions for COPD over the years. He has just been admitted for the fourth time in three months for exacerbation of COPD. Following admission his condition declines rapidly.

Activity 24

- (i) What would you consider John's prognosis at this point?
- (ii) Is this an appropriate time to begin talking to John about the need for advance care planning? Should this discussion have been initiated earlier?

Activity 25

Construct a role play in which you talk to John about his options.

- (i) What information about his illness would you include?
- (ii) How would you begin a discussion about his prognosis, the likely trajectory of his illness, and the importance of making decisions now about treatment interventions?
- (iii) What information does he need about treatment options – eg., in the event of respiratory failure – that would enable him to make decisions about what interventions he would accept or refuse?
- (iv) What family members would you include in the discussion?
- (v) Would you involve other professionals in the discussion?
- (vi) How important is it to consider the capacities and needs of John's wife, who is his primary care-giver? How would you go about making that assessment?

Case Study 2: June

June is a 74 year old widow living in a small town with access to a local GP and hospital. She is diagnosed with non-small cell lung cancer and stage 4 liver metastasis at diagnosis. She has elected not to have any adjuvant therapy. She has a long history of COPD and suffered an acute myocardial infarction in 2003 with no residual cardiac impairment. She has 2 adult children both of whom live out of town. Her husband died 3 years ago and she has become quite isolated.

At the time of the diagnosis June had been functioning well, looking after herself but has no one locally to help or support her.

Activity 26

- (i) What is your assessment of June's situation? What do you think of her decision not to have adjuvant treatment?
- (ii) On the program Norman Swan notes that it is sometimes difficult to know how much depression is playing a part in the sort of decisions made by someone in June's situation? How would you go about trying to differentiate?
- (iii) How would you intervene if you concluded that she was suffering from depression?
- (iv) How would you address the situation if she insisted that her children not be informed of her situation?
- (v) What would you regard as the appropriate treatment and management at this stage?
- (vi) What information does she need to have about the likely trajectory of her illness?
- (vii) What supports would you organise for June at this stage?

Case Study 2 Continued

For the last 6 months June has been seen regularly by the community care nurse. She has had increasing difficulty from dyspnoea and needs increased support to remain at home.

Activity 27

- (i) How would you treat her breathlessness?
- (ii) What medications would you prescribe?
- (iii) What are the likely implications of these medications?
- (iv) What other supports would you consider introducing?

Case Study 2 Continued

June has been losing weight, and is experiencing increasing pain and nausea. She is requiring a continuing higher level of support and sometimes twice daily visits.

Activity 28

- (i) In the program discussion, Dr Rhee suggests that taking a good pain history is often neglected at this point. Do you agree, and if so, why do you think this might be?
- (ii) How would you treat her symptoms at this point? Would you admit her to hospital?

Case Study 2 Continued

June is admitted to hospital and the first night is awake at 2am confused and yelling out.

Activity 29

- (i) How would you understand what's happening?
- (ii) What would be your treatment recommendations?
- (iii) What medications would you use?
- (iv) What sort of end of life care would you offer her?

Activity 30

- (i) There is mention on the program of fatigue being a difficult symptom to treat medically. Construct an information leaflet on management of fatigue that you might give to particular patients and their caregivers. (See resources such as those put out by Palliative Care Victoria: www.pallcarevic.asn.au/general-public/painsymptom-management/)
- (ii) Have a look at Box 10 (“Discussing future symptoms and symptom management” in the *Clinical Guidelines*).

Chapter 5

Chapter 5 Impact on Caregivers

Caring for a patient with terminal illness at home involves a considerable commitment on the part of family caregivers.

A recent Australian study (Hudson 2003) of 106 family caregivers involved in metropolitan home-based palliative care found that “two-thirds were women and two-thirds were caring for a spouse or partner. Their mean age was 60 years (range, 21–84 years), three quarters were born in Australia and a fifth had a household income of less than \$10 000 per annum. Less than half were retired, and about a quarter had stopped work or taken part-time work in order to care for the patient at home.” As the author notes, this data suggests the considerable commitment undertaken by those who are involved in home-based palliative care.

Hudson nominates the following responsibilities that the caregiver is often faced with:

- personal care (hygiene, feeding);
- domestic care (cleaning, meal preparation);
- auxiliary care (shopping, transportation);
- social care (informal counselling, emotional support, conversing);
- nursing care (administering medication, changing catheters); and
- planning care (establishing and coordinating support for the patient).

Activity 31

- (i) What are the likely implications for caregivers of this range of responsibilities?
- (ii) What sort of psychological and social effects on caregivers would you anticipate?
- (iii) Hudson notes that the social and emotional needs of caregivers are often overlooked, given both the medical concerns about the patient, and the caregiver’s own concerns. What supports are available for caregivers in your community?
- (iv) What other health professionals are available in your community to be involved in a supportive role?
- (v) What role can the GP play in ensuring that caregivers are adequately attended to?

Chapter 6

Chapter 6 Palliative and End of Life Care for Special Groups

Indigenous Peoples

Main Points from the Discussion

- Prof Currow notes some particular issues for Indigenous peoples regarding palliative and end of life care: it is a group of people who is dying younger than the rest of the community; they are dying of chronic diseases rather than cancer; and there are specific issues to do with cultural background that are important for health care professionals to understand
- Decision-making can often involve extended family or wider community discussion
- It is really important to involve Aboriginal health workers where possible

Activity 32

What would you identify as the cultural considerations that need to be considered when working with Indigenous people and their families around issues of palliative and end of life care?



Some important resources include:

- (i) Learning Guides and Resource Kits for Aboriginal Health Workers put out by the PEPA (Program of Experience in Palliative Care) website:
<http://www.pepaeducation.com/ATSIHW/>
- (ii) Maddocks, I and Rayner R.G., “Issues in palliative care for Indigenous communities” MJA 2003; 179 (6 Suppl): S17-S19
- (iii) A document on Advance Care Planning with Aboriginal and Torres Strait Islander peoples at
http://www.caresearch.com.au/Caresearch/Portals/0/Documents/WhatisPalliativeCare/NationalProgram/RespectingPtChoices/Aboriginal_Torres_Strait_Islander_Advance_Care_Planning%20.pdf
- (iv) A Department of Health and Ageing Resource Kit on Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander Peoples
<http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-indig-resource.htm>
- (v) A Rural Health Education Foundation program on Palliative Care for Indigenous People
http://www.rhef.com.au/programs/program-1/?program_id=139&group_id=5

Paediatric Palliative Care

In 2002 the Department of Health and Ageing funded a review of Australian paediatric palliative care. The report found that the needs of dying children have not been addressed to the same extent as the needs of dying older patients. Under the National Palliative Care Program the Australian Government has funded a number of projects to improve the understanding of palliative care for children and young people and support families of children with a life-limiting illness.

These include *Journeys – Palliative Care for Children and Teenagers*. This document is an information resource that aims to better prepare and equip families and carers of children with a life-limiting illness. It provides information on other services and resources to help best meet the needs of these families. *Journeys* was written in consultation with specialist clinicians and families. www.palliativecare.org.au/Default.aspx?tabid=1120

A 2003 article in MJA (Hynson et al) reported that “In developed nations, it is estimated that, each year, 10 per 10 000 children aged 0–19 years will require palliative care. This means that, at any one time, up to 5300 Australian children in this age group will have a life-limiting condition, about half of whom may need “active” palliative care”.

The report also makes the following points:

- Speaking with children about illness and death is difficult and requires careful attention to developmental issues.
- Parents are generally more involved as direct caregivers and decision makers than in the adult setting. Correspondingly, when a child dies, parental grief is more intense than the grief experienced in response to other forms of loss.
- Children’s inability to act autonomously and their necessary reliance on parents as surrogate decision makers complicates the resolution of ethical questions in paediatric practice. There are occasions when parents insist on treatment that health professionals view as inappropriate. Conversely, parents may refuse treatment of potential benefit to the child.
- Most families choose to spend as much time at home as possible. The home environment also provides families with the security of a familiar environment, free from the disruption of hospital routines. Children generally prefer to be at home among their own toys, pets, family members and friends.
- The holistic approach of palliative care requires a multidisciplinary team approach to ensure meticulous attention to planning, coordination and communication. The designation of a key worker to coordinate care is essential, as a large number of care providers and agencies may be involved across a range of care settings.

Activity 33

- (i) What do you think are the main considerations in talking directly with children about serious illness and death? (See discussion on this issue in Paediatric Palliative Care in Australian Doctor, May 2004
http://www.australiandoctor.com.au/htt/pdf/AD_HTT_039_-46_MAY07_.04.pdf)
- (ii) What do you think are the implications for health workers of the close involvement of parents with their child's illness, care, and eventual death?
- (iii) How would you describe the GP's role with the family?
- (iv) The 'holistic' nature of palliative care with children is often emphasized. Who would you see as essential members of the multidisciplinary team?



Some important resources include

- See CareSearch page on palliative care knowledge network
<http://www.caresearch.com.au/Caresearch/LinkClick.aspx?fileticket=auSCxFUyo58%3D&tabid=433>
- Special edition on Paediatric Palliative Care in Australian Doctor, May 2004
http://www.australiandoctor.com.au/htt/pdf/AD_HTT_039_046_MAY07_04.pdf

People with Dementia

According to the AIHW Report on Dementia in Australia (2007), there are over 100 illnesses and conditions that can result in dementia. After the age of 65 the likelihood of living with dementia doubles every five years and it affects 24% of those aged 85 and over. It is the greatest single contributor to burden of disease due to disability at older ages.

The cognitive, psychiatric and behavioural manifestations of dementia can include:

- memory problems, especially for recent events (long-term memory usually remains in the early stages)
- communication difficulties through problems with speech and understanding language, confusion, wandering, getting lost
- personality changes and behaviour changes such as agitation, repetition, following
- depression, delusions, apathy and withdrawal.

See the Report at <http://www.aihw.gov.au/publication-detail/?id=6442467941>

Activity 34

(i) What are the consequences for discussions of end of life care and advance care planning of these various manifestations of dementia?

(ii) Dr Julian Hughes (2010) has commented about dementia patients that research indicates:

They are less likely to receive palliative medication and pain relief, less likely to have attention paid to their spiritual and religious needs, and less likely to be referred to palliative care specialists than people who don't have dementia.

What is your reaction to this comment and what are the consequences for the GP?

(iii) Research by Sachs et al (2004) indicates that patients with dementia often die with inadequate pain control. How would you go about talking with your patients and their carers about this issue?

(iv) Clearly, the increasing likelihood of dementia as the population ages would support the notion that it is useful to introduce advance care planning as part of routine medical care. Such discussions are obviously more difficult as the severity of dementia symptoms increase. How would you introduce the possibility of advance care planning with someone showing signs of mild dementia?

(v) How would you talk to the family of a patient with severe dementia about palliative and end of life treatment options?



Some important resources include

- Look at the self-learning module provided by Palliative Care Australia on *advance care planning* in a Residential Aged Care facility
<http://agedcare.palliativecare.org.au/LinkClick.aspx?fileticket=09xRm6%2BkFVs%3D&tabid=1178&mid=1734>
- The Department of Health and Ageing funded the ACH Group in South Australia to develop a Palliative Care Dementia Resource Kit. It is available as a free download from www.ach.org.au/site/page.cfm?u=469
- CareSearch also offers information about palliative care for patients with dementia
- See the resources provided by Alzheimer's Australia (<http://www.alzheimers.org.au>)
- The US website Palliative Care Dementia Resources also provides a number of helpful resources www.pdcronline.com/index.php

Chapter 7

Chapter 7 Ethical Issues in Palliative and End of Life Care

Prof Wendy Rogers makes a number of comments on the program regarding ethical issues in palliative and end of life care.

- Ethical issues fall into several categories:
 - (i) those associated with patient care (such as understanding a patient's preferences; minimising suffering; acting in the patient's best interests);
 - (ii) those associated with structural issues such as equity and resource allocation;
 - (iii) and specific issues such as those concerned with the difference between euthanasia, assisted suicide, and a patient's right to refuse treatment
- The importance of developing honest and trusting relationships between patients and health care professionals
- Being able to provide compassionate care that meets patient needs as well as one can within the law
- Decision making needs to take account of all people involved, not only patients and medical personnel, but carers as well
- Doctors are not obliged to provide treatment if they do not believe it is in the patient's best interests
- Sometimes it can happen that a patient is deemed competent if they comply with medical care and incompetent if they don't
- If a patient is competent, then taking them to hospital against their will, or giving them treatment against their will, constitutes assault and battery
- If a patient is deemed incompetent, then there is a duty of care on the part of medical personnel

Activity 35

- (i) Review the comments and select two to consider in more detail.
- (ii) See the discussion of ethics on the *Respecting Patient Choices* website at http://www.respectingpatientchoices.org.au/index.php?option=com_content&view=article&id=27:the-ethics-of-advance-care-planning&catid=3:more-information&Itemid=28
- (iii) "Terminal sedation" refers to the use of sedative drugs to induce unconsciousness in terminally ill patients in order to relieve suffering, including anxiety, when other attempts at relief have failed. Do you consider this as an ethical intervention with dying patients? What would be the arguments for and against?

Take-home Messages (from the original program)

Professor Wendy Rogers: Respect the patients' choices where you can, find out what they want, communicate and care compassionately.

Dr Joel Rhee: I agree. It's very important to communicate well with everybody - the patient, carers and everybody involved, and to set goals that everybody understands and hopefully agrees on.

Ms Nikki Johnston: It's important to remember that dying is a natural part of life, and having an advance care plan in place in a timely manner, before we reach a crisis, can help end of life care to be a lot better.

Professor David Currow: It's good to be a mortal. This is a very individual journey for people and we need to understand what's important for them in the context of their life, their families, their friends, and their hopes at this time in their life.

Activity 36

Review the Learning Objectives below.

After working through the Learning Guide, participants will be able to:

- Identify the issues and concerns for patients and their families at end of life
- Effectively communicate aspects of end of life treatment and care for patients and families
- Understand the purpose and principles of *advance care planning*
- Describe the role of the multidisciplinary team in providing end of life care

- (i) How well do you think you met these objectives? What further information would be helpful? How would you locate this?
- (ii) What is your 'take-home message' on completion of the Learning Guide?

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Resources Embedded on DVD

The following is a list of the resource material that has been embedded on the DVD:

1. Clinical Practice Guidelines

Clayton, J.M., Hancock, K.M., Butow, P.N., Tattersall, M.H.N., and Currow, D.C.

“Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers”

MJA 2007; 186 (12 Suppl): S77-S108

2. Tasmanian Adult Palliative Care Formulary

This formulary has been developed by the Department of Health and Human Services, Tasmania, to provide information for those healthcare professionals involved in prescribing and caring for adult patients receiving palliative care.

3. CareSearch Pamphlets and Fact Sheets

CareSearch Supporting Health Professionals

This provides an overview of the main sections and how they can help all health professionals looking for information or resources for patients and their families.

CareSearch GP resources

This provides information on the resources available within the GP Hub and highlights some of the common concerns that GPs face.

CareSearch Nurses Hub

This sheet overviews what is in the Nurses Hub and why it can help any nurse in any health setting who is caring for someone at the end of their life.

CareSearch Six Steps

This sheet provides health professionals with a guide to how to find the type of evidence they need.

CareSearch Patient Carer Brochure

This is a general introduction for patients and families about resources on CareSearch and how information helps.

CareSearch End of Life brochure pack

Information on a set of CareSearch resources that health professionals can order free of charge to give to their patients.

4. Respecting Patient Choices Resources

You will find a Leaflet for Patients and an Information Booklet from Respecting Patient Choices. These materials are from the ACT section of the website, but are representative of the sorts of materials you can find in any of the state-specific website areas.

5. Order Forms from the Australian Government for free palliative and aged care publications

6. A promotional video about PEPA (Program of Experience in the Palliative Approach)

7. A copy of this Learning Guide