

Patient Management Task Force

Paper No. 7

**The Right Health Care:
Balancing Clinical Science
and Decision Making
with Individual Wishes**

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Introduction

There is but one way to enter this life, but the gates of death are without number.

(proverb)

Because of advances in medicine, people now live longer than ever before, often surviving quite well with conditions that they previously may have died from (or died sooner from). But these advances also mean that as death nears there are now more options than ever for extending a person's life, irrespective of its quality.

The Journal of the American Medical Association put it this way:

'Medical advances and increasing life expectancy have paradoxically distanced physicians and nurses from their roles early in the century, when they focused on helping dying patients but had little else to offer. Now, effective treatments discovered through research on middle-aged adults apply to older adults, bringing health promotion and prevention to adults in their late years. This success raises important new questions. At what point should clinicians shift from a preventive focus to a palliative one? How can the uncertainties of prognosis at the end of life be managed?'¹

In Victoria, about 15,000 deaths occur in hospitals every year (half of all deaths). Making the right decisions about the best treatment for patients is part of the daily life of every doctor. However, for patients whose quality of life following treatment is expected to be very poor, making these decisions can present profound dilemmas for hospitals, hospital doctors and patients' families. In some cases, lack of consultation with patients or their carers (where that course is possible) can lead to people receiving treatment that, if asked, they would far prefer not to have received. The converse can also occur.

Making the right decisions about the best treatment for patients is part of the daily life of every doctor. However, for patients whose quality of life following treatment is expected to be very poor, making these decisions can present profound dilemmas for hospitals, hospital doctors and patients' families.

While concerns about the allocation of limited health care resources are an ever-present consideration, concerns about the well-being of patients are likely to be much more significant. Research in the USA suggests that physician and hospital costs for people in their 80s and 90s are lower than for younger groups, with extensive technological interventions more likely to go to people with good functional status and prospects for recovery rather than to older terminally ill people.²

Over the past few years there has been much interest in the USA on care at the end of life. A recent issue of the Journal of the American Medical Association was focused entirely on caring for patients at the end of life.³

1 Winker, MA, Flanagan A. 'Caring for patients at the end of life', *JAMA*, 282: November 24, 1999. Also @ <http://jama.ama-assn.org/issues/v282n20/full/jed90097.html>

2 Alliance for Aging Research. 1997. *Seven Deadly Myths: Uncovering the Facts About the High Cost of the Last Year of Life*.

3 *Journal of the American Medical Association*. 284:19, November 15, 2000. Also at <http://jama.ama-assn.org/issues/v284n19/toc.html#a3>

The US Institute of Medicine's Committee on *Care at the End of Life* published a major review in 1997.⁴ Two Breakthrough Series Collaboratives in the United States, on Improving Care at the End of Life, have brought together over 80 hospitals, hospices, outpatient clinics, and home care agencies to learn about improvements in end of life care and accelerate the change process within their care systems.⁵ Education for Physicians on End-of-life Care is another initiative in the US that offers detailed guidance for physicians and others involved in managing patients at the end of their life.⁶

The Task Force believes that the sensitive and proper management of patients at the end of life is an important feature of hospitals' and health care professionals' objective of providing the right care in the right place at the right time.

The Patient Management Task Force

An objective of the Task Force is to engage actively with hospital management and clinicians in dealing with problems of access to emergency services and elective surgery—both at the individual health service level and in professional forums.

The Patient Management Task Force was set up in November 2000 to identify specific areas for improvement in in-hospital patient management processes and to advise on the system factors that will encourage the adoption of best practice in patient management. An objective of the Task Force is to engage actively with hospital management and clinicians in dealing with problems of access to emergency services and elective surgery—both at the individual health service level and in professional forums. The Task Force is also seeking to obtain views from a wide range of stakeholder groups on effective solutions. The Task Force's terms of reference and membership are at Appendix 1.

The Task Force is focusing on major metropolitan hospitals⁷ and is carrying out its work in three stages:

- Stage 1, the information gathering stage, is now complete. An overview paper *Serving the Needs of the Patient: Better Patient Management in Melbourne's Public Hospitals* has been released.

4 Marilyn J. Field and Christine K. Cassel, Editors. 1997. *Approaching Death: Improving Care at the End of Life*, National Academies Press. <http://www.nap.edu/catalog/5801.html>

5 Institute for Healthcare Improvement. 2001. *The Vision of Improved End of Life Care*. Also @ <http://www.ihl.org/resources/eol>

6 The EPEC Projects at <http://www.epec.net>

7 The Alfred Hospital (Bayside Health); Austin and Repatriation Medical Centre; Box Hill, Maroondah and Angliss hospitals (Eastern Health); Frankston Hospital (Peninsula Health); Monash Medical Centre (Clayton and Moorabbin) and Dandenong Hospital (Southern Health); Northern Hospital (Northern Health); Royal Melbourne Hospital (Melbourne Health); St. Vincent's Hospital; Western Hospital and Sunshine Hospital (Western Health)

- Stage 2 involves producing papers on ‘action areas’ for consideration and comment by the field. Papers are being published on the following topics:
 - Emergency Services
 - Ambulatory Care
 - Multi-day Medical and Elective Surgery Patients
 - Services for the Older People
 - Improving the System
 - Care Decision Making
- Stage 3 will be the preparation of a short final paper incorporating a summary of the principal themes of the Task Force’s work, key areas for action and any changes to the views of the Task Force as a result of comments received.

Providing Feedback

The Patient management Task Force invites you to submit your views and comments on this paper and its recommendations to:

Patient Management Task Force
Level 16, 555 Collins Street
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Email: patient.management@dhs.vic.gov.au

Recommendations

1. The Department of Human Services should ask an appropriate body, such as the Health Services Commissioner, to hold a workshop involving hospital clinicians, ethicists, general practitioners, the public advocate, representatives of residential aged providers, palliative care specialists and consumers to consider ways of improving awareness and use of the *Medical Treatment Act 1988*.
2. The Department of Human Services should work with metropolitan health service chief executives to establish a collaborative forum on end of life care, with the aim of identifying and consistently implementing best practice.
3. The Department of Human Services should establish a consultative process involving relevant clinical colleges, professional associations and consumer groups to develop guidelines along the lines of the revised Dying with Dignity guidelines being prepared in New South Wales and the United Kingdom guidelines on cardiopulmonary resuscitation.
4. The Department of Human Services should ask the relevant accreditation agencies to review their accreditation guidelines to make it a requirement that patients and their families are made aware of their rights under the *Medical Treatment Act 1988*.
5. The Department of Human Services should encourage State-funded aged residential care facilities to replicate the Canadian trial regarding provision of information and support to residents regarding end of life choices.
6. Metropolitan health services should review their processes for communicating with seriously and terminally ill patients and their families, and ensure that appropriate support for health care professionals is provided, including training in communication skills.
7. The professional and peak bodies representing general practitioners and residential aged care providers should ensure that adequate communication skills training is available for dealing with end of life care and decision making.

Observations and Findings

1. There is variable awareness in Victorian hospitals, and in the wider community, of the provisions of the *Medical Treatment Act 1988*.

In 1985, intense public debate on euthanasia and the care of terminally ill people led the Victorian Government to ask the Social Development Committee of Parliament to inquire into legal and practical issues concerning people's right to die by refusing medical treatment.

The Committee's Inquiry extended over 18 months, heard over 150 witnesses, received almost 1400 written submissions, and resulted in the publication of two reports^{8,9} and 31 recommendations. A key outcome was the enactment of legislation, the *Medical Treatment Act 1988*. The aim of the Act was to clarify and codify existing common law rights for patients to refuse unwanted medical treatment and to establish a process for clearly indicating a decision to refuse medical treatment.

The Right to Refuse Treatment

Advance medical directives, or advance directives, are legal documents, mainly used in the United Kingdom and the United States of America, which allow patients, or prospective patients, to specify in advance the circumstances where they no longer wish to have medical treatment of a general or specific kind. Such provisions also exist in other Australian States, for example under Queensland's *Powers Of Attorney Act 1998*.

The equivalent instrument in Victoria is a 'Refusal of Treatment Certificate' under the *Medical Treatment Act 1988*.

A Refusal of Treatment Certificate differs from an advance directive in several ways. It can only be made in relation to a current medical condition, ie it cannot be made while healthy in anticipation of a future condition arising, and it ceases to be effective if the person's medical condition that gave rise to the certificate has changed to the extent that this original condition no longer applies.

The *Medical Treatment Act* also excludes palliative care from the definition of 'medical treatment' and so the right of a patient to refuse treatment does not extend to a right to refuse palliative care.

Where a Refusal of Treatment Certificate has been completed, the Act indemnifies a medical practitioner, acting in good faith, from prosecution for failing to perform or continue treatment that is at odds with the patient's wishes. The Act also provides that if a doctor acted contrary to a patient's wishes expressed in a Refusal of Treatment Certificate, then he or she could be charged with an offence (medical trespass).

The aim of the Medical Treatment Act 1988 was to clarify and codify existing common law rights for patients to refuse unwanted medical treatment and to establish a process for clearly indicating a decision to refuse medical treatment.

8 Social Development Committee. 1986. *First Report on Inquiry into Options for Dying with Dignity Incorporating a Discussion paper: A Range of Views on Options for Dying with Dignity*. Parliament of Victoria.

9 Social Development Committee. 1986. *Inquiry into Options for Dying with Dignity Second and Final Report*. Parliament of Victoria.

Enduring Power of Attorney

One of the elements of the Act is the provision for the patient to assign his or her decision-making authority to another party via an Enduring Power of Attorney (Medical Treatment). This means that as a patient's circumstances change, perhaps in unpredictable ways, and they are not competent to judge their preferred course, there is another party who is able to act on their behalf.

The Committee's original proposals to allow a patient to appoint an agent to make decisions on their behalf were initially not passed by the Parliament, however an amendment in 1990 reinstated these provisions.

Despite the provisions of the Act, there may still be many people being resuscitated contrary to their wishes. The Task Force was given an example of this:

An elderly woman in a nursing home who had expressed a desire not to be resuscitated was brought to an emergency department by ambulance following a cardiac arrest. She was subsequently intubated and acute medical treatment commenced. She was revived, treated and returned to her nursing home and lived for several more months.

The Task Force considers that there may be insufficient awareness in Victorian hospitals, and in the wider community, of the provisions of the *Medical Treatment Act*. For example, although the Better Health Channel, and the Clinicians Channel have links to palliative care service providers, neither site publishes information specifically on care and decision-making processes at the end of life.

With the Act having now been in place for over a decade, it is timely to take stock of the extent to which its provisions have been exercised. It would also be appropriate to review the extent to which the other recommendations made by the Social Development Committee have been implemented. For example, the Committee made a number of recommendations about codes of practice, and educational initiatives to ensure patients were fully aware of the options available to them. However, it is not clear that these have been implemented to the extent the Committee envisaged.

One of the outcomes of such a review could be the conduct of a Breakthrough Collaborative on end of life care such as has been conducted in the US.¹⁰

¹⁰ Institute for Healthcare Improvement 2001. *The Vision of Improved End of Life Care*. Also at <http://www.ihl.org/resources/eol>

Recommendations

1. The Department of Human Services should ask an appropriate body, such as the Health Services Commissioner, to hold a workshop involving hospital clinicians, ethicists, general practitioners, the public advocate, representatives of residential aged providers, palliative care specialists and consumers to consider ways of improving awareness and use of the *Medical Treatment Act 1988*.
2. The Department of Human Services should work with metropolitan health service chief executives to establish a collaborative forum on end of life care, with the aim of identifying and consistently implementing best practice.

2. Guidelines could assist health care professionals in working with patients at the end of life and their carers.

In 1993 the New South Wales (NSW) Health Department released *Dying with Dignity: Interim Guidelines on Management*, which aimed to assist health care workers in making decisions about the care of dying patients. A discussion document was released in November last year that sought comments from the public on revising the guidelines.¹¹

In the United Kingdom (UK), guidelines on *Decisions Relating to Cardiopulmonary Resuscitation* were first published in 1993 and revised twice since, with the most recent revision reflecting the European Convention on Human Rights.¹² As a result of public concern that doctors were routinely writing 'Do Not Resuscitate' on the notes of older patients, allegedly because of their age, the UK Government now requires every hospital to use these guidelines as a basis for developing and implementing local policies on resuscitation.¹³

The UK guidelines outline legal and ethical standards for planning patient care and decision-making processes in relation to cardiopulmonary resuscitation. The guidelines cover situations where decisions are made in advance and form part of the patient's care plan, and emergency situations where no advance care planning (advance directive) has been made.

The Social Development Committee's *Dying with Dignity* report also included a recommendation that the National Health and Medical

Even where a patient's views are known, there can still be an ambiguity or uncertainty that may lead to care being provided that could be contrary, or construed as contrary to the patients wishes or best interests. The ability of hospitals to improve care at the end of life would benefit from clear guidelines for decision-making.

11 NSW Health Department 2000. *Dying with Dignity: Revised Draft Guidelines for Clinical Decision Making at the End of Life*. Government of NSW. Also at <http://www.health.nsw.gov.au/>

12 *Joint Statement on Cardiopulmonary Resuscitation*. Also at <http://web.bma.org.uk/public/pubother.nsf/webdocs/vw/cpr>

13 Department of Health. Government Reinforces Patients' Rights On Resuscitation Decisions, 5 Sept, 2000, Press Release reference 2000/0490. Also at <http://tap.ccta.gov.uk/doh/intpress.nsf>

Research Council should develop guidelines to assist medical staff decide when to apply cardiopulmonary resuscitation. Such guidelines were not ultimately developed, and the Task Force believes that renewed consideration should be given to doing so.

Recommendation

3. The Department of Human Services should establish a consultative process involving relevant clinical colleges, professional associations and consumer groups to develop guidelines along the lines of the revised Dying with Dignity guidelines being prepared in NSW and the UK guidelines on cardiopulmonary resuscitation.

The recent policy moves in the UK have also included a requirement for the Commission for Health Improvement to look specifically at the quality of resuscitation decision-making processes as part of their inspection program of local hospitals.

In Australia at present, the accreditation requirements for hospitals (EQuIP) and residential aged care providers refer to policies on patient rights, including the right to refuse treatment, but these are set out in general terms. In the case of the EQuIP guidelines, refusal of treatment is simply one item in a list of ethical issues that may, rather than must, be addressed.

A recent randomised controlled trial in Canada found that the systematic implementation of an advance directive program in nursing homes reduced use and costs of healthcare services without affecting patient satisfaction.¹⁴ The most interesting result of the study was thought by one commentator to be the increased awareness by patients, their families and healthcare providers of the many management options available, even when technology intensive interventions other than cardiopulmonary resuscitation are no longer desired.¹⁵

One potentially effective step would be to revise the relevant accreditation guidelines to ensure that health care providers are *obliged* to ensure that patients and their families are fully aware of the provisions of the *Medical Treatment Act*.

Recommendations

4. The Department of Human Services should ask the relevant accreditation agencies to review their accreditation guidelines to make it a requirement that patients and their families are made aware of their rights under the Medical Treatment Act 1988.

14 Molloy DW, Guyatt GH, Russo R. 'Systematic Implementation of an Advance Directive Program in Nursing Homes: A Randomised Controlled Trial', JAMA, 283:1437-44. 15 March 2000. Also @ <http://jama.ama-assn.org/issues/v283n11/abs/joc90890.html>

15 Beghe C. 'Commentary on "Systematic Implementation of an Advance Directive Program in Nursing Homes. A Randomised Controlled Trial"'. *Evidence-Based Medicine*, 5:182, November/December 2000.

5. The Department of Human Services should encourage State-funded aged residential care facilities to replicate the Canadian trial regarding provision of information and support to residents regarding end of life choices.

3. Good communication between patients/carers and health care professionals is essential to a common and informed understanding of the options for and wishes of people at the end of life.

The latest *Annual Report of Victoria's Health Services Commissioner* includes an exploration of issues surrounding communication between patients and health service providers and end of life decisions.¹⁷ Given its relevance, this section of the report is set out in full here.

'Death is an inevitable part of life. We need to talk about it.'—Health Services Commissioner¹⁶

'Poor communication continues to be the pre-eminent issue in complaints against health service providers. Where complaints are related to the circumstances preceding death they involve issues of particular sensitivity. These complaints cover a variety of topics and questions that arise include:

Were the patient and family given all the available information to make an informed decision about treatment options?

Was the patient's pain managed optimally?

Could the patient have survived the final illness if different management had been used?

Was the decision to withdraw treatment or not to resuscitate made in consultation with everyone involved in the care, including family members?

Was the decision to withdraw treatment reasonable?

In most instances, after the Health Services Commissioner has obtained the hospital records and, perhaps, spoken to an independent expert about the care provided to the patient, it seems likely the care given was reasonable. However it is also apparent that the medical decisions were not fully discussed with the patient or the family. The reasons for this are unclear. It may be that health professionals are so focused on treating and curing patients they cannot bring themselves to communicate well or even talk frankly about the inevitability of death. The impetus to cure is understandable but doctors, in common with all people, have to recognise the reality of death and to communicate with their patients about it'.

16 Health Services Commissioner. *Annual Report 1999–2000*. p. 9. Government of Victoria.

17 Health Services Commissioner. *Annual Report 1999–2000*. pp. 9–11. Government of Victoria.

A man was seriously ill and dying. The day before his death a doctor suggested to the family that the man be transferred to a rehabilitation unit. The family became very confused because they could see how close to death their father was. One family member asked the doctor, 'Are we talking about the same person?' The family said the mixed messages they got from hospital staff contributed to their grief and inhibited better co-operation between the various family members.

The sad truth is that death is inevitable for us all, no matter how good the quality of our health care. When that final stage is reached, people need as much information and advice as during other stages of their life. Patients and their families are individuals and have varying needs and desires. Some may prefer to leave decision making to the experts, but there is usually at least one close family member who does need, and want, to know.

A woman complained that she had never been advised that her husband was dying. She was aware that he was very sick but no one mentioned how close to death he was. She was sure the medical staff knew but no one talked to her about it.

While significant advances have been made in understanding palliative care issues not everyone dies attended by trained palliative carers. The Commissioner's Report found that where trained palliative carers are involved much better communication is provided. The role of communicating with the dying and attending to the needs of their loved ones is too important to be done simply by whoever happens to be available at the time.

Health professionals who are interested in this aspect of health care require specialist training to ensure this difficult communication is done as well as possible. This does not guarantee that no one would ever complain about the circumstances of a loved one's death, but it might go a long way to reducing the anger that so often goes hand in hand with grief.

A man was admitted to hospital with a suspected heart attack. He received treatment in the intensive care unit (ICU) and appeared to be recovering well. He was moved to a general ward where he continued to be treated but subsequently died. His family believed inadequate care was given. On further investigation and with the assistance of an independent medical opinion, it was established that ICU staff had failed to communicate with the family just how seriously ill the man was. The medical records indicated that they were aware just how critical his condition was. The family considered that a warning and an explanation of the treatment plan would have lessened their trauma. The Hospital has responded by changing its procedures and providing specially trained nurses to deal with future problems.

The Task Force agrees that specialised training can help doctors and nurses to communicate better with patients. All metropolitan health services will have professional development units of some kind whose responsibility it is to ensure that necessary staff training and development opportunities are provided. However, it would be appropriate to review the extent to which these meet the specific needs surrounding discussion of end of life decision-making.

While good communication skills can be learned, junior staff, or those who do not often find themselves in a position where a discussion is needed, may benefit special training and participation in such discussions with senior staff.

The Task Force has learned of one initiative to be trialled at the Alfred Hospital, in association with the Baker Institute of Medical Research. The Hospital intends to fund a Clinical Ethics Service as a pilot project. It will be a 24 hour on-call service available to assist clinicians, especially junior clinicians, who need to discuss end-of-life care decisions with patients, or make difficult decisions faced with other ethical dilemmas.

Victoria's multicultural diversity also means that many patients may have views on death and dying that are different from people from the mainstream Judaeo-Christian background. The need for communication about end of life issues to take account of culturally sensitivities also needs to be recognised.

Recommendation

6. Metropolitan health services should review their processes for communicating with seriously and terminally ill patients and their families, and ensure that appropriate support for health care professionals is provided including training in communication skills.

Raising issues of death and dying with patients and/or their families not only requires tact and sensitivity, but also sufficient time for the issues to be explored, a quiet place and, sometimes, interpreting skills.

The provision of good palliative care in residential aged care facilities requires good communication skills on the part of both general practitioners and nurses, access to specialised support services, where necessary, and the time to discuss the issues with patients and their families.

Palliative care services are coordinated medical, nursing and allied health services for people who are terminally ill, delivered where possible in an environment of the person's choice, and which provide physical, psychological, emotional and spiritual support for patients' families and friends. Hospice and palliative care includes grief and bereavement support for the family and other carers during the life of the patient, and continuing after death.

While there has been a substantial expansion of palliative care services over the past decade, situations can still arise where dying people are brought into hospital when palliative care would be better provided where they live. Around a quarter of all deaths in Victoria (some 7,500 a year) take place in residential care facilities. The provision of good palliative care in residential aged care facilities requires good communication skills on the part of both general practitioners and nurses, access to specialised support services, where necessary, and the time to discuss the issues with patients and their families. The growing dependency of residents in nursing homes and in some cases, a lack of experienced staff can mean that these conditions are not always met. The Task Force believes that the adoption of its recommendations in this and other papers represent tangible ways of addressing this issue.

Recommendation

7. The professional and peak bodies representing general practitioners and residential aged care providers should ensure that adequate communication skills training is available for dealing with end of life care and decision making.

Appendix 1: Patient Management Task Force

Terms of Reference

1. To identify essential organisational and patient management practices that should be in place in all hospitals.
2. To determine the extent to which these practices are occurring in metropolitan health services, identify specific areas where improvements should occur and advise on how these improvements could be quickly achieved.
3. To determine key indicators of good patient management practice and the benchmarks that should be achieved by health services.
4. To advise on incentives and other strategies that could be used to encourage health services to achieve benchmarks.
5. To communicate and engage with representative bodies of health professionals, practitioners, managers and other stakeholders in identifying and implementing good patient management practices.

Membership

Dr Michael Walsh (Chair)—Chief Executive, Bayside Health

Dr Jim Breheny (Deputy Chair)—Chair, Austin and Repatriation Medical Centre Board

Professor Gordon Clunie—Chair, Ministerial Advisory Emergency and Critical Care Committee

Ms Ella Lowe—Executive Director Operations, Peninsula Health

Mr Robert Burnham—General Manager, Northern Hospital

Dr Heather Buchan—Assistant Director, Quality and Care Continuity Branch, Acute Health Division, Department of Human Services

Mr Geoff Lavender—Regional Director, Barwon-South Western Region, Department of Human Services (Project Director)

Project Team

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Ms Julie La Gamba, Acute Health Division, Department of Human Services