Conflict Resolution in End of Life Settings (CRELS)

Final CRELS Project Working Group Report
Including Consultation Summary

Contents

Acknowledgements

The CRELS Working Group was impressed by the degree of enthusiastic engagement with this project during consultation. The importance of improving this difficult aspect of clinical care was commented on by many who provided advice.

The Working Group wishes to thank all those who provided feedback for their time, thoughtful participation and insightful comments.

Letter from CRELS Working Group Chair
to the Director-General for Health

NSW✚HEALTH

Professor Debora Picone AM
Director-General
NSW Health
73 Miller Street
North Sydney NSW 2060

Dear Professor Picone

Please accept this *Conflict Resolution in End of Life Settings (CRELS) Project* Working Group Report. Part of the background to this project was a sense from some senior clinicians that the NSW Health *Guidelines for end of life care and decision-making* introduced the concept of "shared decision making" at the end of life, but gave insufficient guidance as to how best to achieve consensus, or what to do when consensus was not forthcoming. Conflict may arise under these circumstances, and some high-profile court cases in NSW showed how serious this could become. This Working Group was set Terms of Reference that gave it scope to look at factors provoking end of life conflict in adult and paediatric settings, and at ways to reduce the risk of this conflict escalating.

Despite the increasing frequency and complexity of end of life decisions made by clinicians in NSW, the Working Group found no evidence of a surge in conflict or of a crisis of public confidence. However, all the people involved in this Report took end of life conflict very seriously, and felt that when it occurred it had a strong negative impact on all concerned, which was sometimes perpetuated over years or even generations.

In summary, end of life conflict is an uncommon but potentially grave problem for all of us. In looking at possible ways to prevent, mitigate or manage EOL conflict, the Working Group was gratified to find a large number of plausible strategies. In some cases these came as suggestions from experts or the public, and others are to some degree evidence-based. In categorising the recommended strategies, we chose to use "short, medium and long term". This is meant to reflect a feeling from the Working Group that some strategies were more urgent, and perhaps more immediately practicable than others. It does not imply that the longer term recommendations are graded as less important. In line with our Terms of Reference, the Working Group also identified and prioritised a number of areas where further consultation and investigation may be required.

The Working Group would like to thank NSW Health for supporting this investigation, and all the doctors, nurses, social workers, parents and members of the public who gave their time so generously. Finally, as Chair of the CRELS Working Group, I would like to thank all Working Group members without whose expertise and willingness to critically examine and debate a host of very complex issues, this process would have not produced such a comprehensive review and constructive way forward.

Yours sincerely

Dr Peter Saul
Chair, CRELS Project Working Group
Senior Intensivist, John Hunter Hospital
Newcastle NSW

SECTION 1

Executive Summary

Decisions to limit use of life-sustaining treatments for dying patients are made every day in NSW hospitals and other care settings. Most of these negotiations go well and agreements are reached between patients, families and the health care team. However, conflicts can and do happen. These conflicts may occur within families, between health professionals and treating teams, and between families of patients who have lost capacity and treating teams. Occasionally they directly involve a patient with capacity or border-line capacity. Evidence[1] suggests that conflict in any of these loci contributes to a poor outcome. In this Report, 'conflict' should be taken to include any or all of these settings. We have defined conflict broadly, as a failure to achieve consensus on the goals of care and related treatment at the end of life, despite allowing time and holding reasonable repeat discussions between involved parties.

Sometimes end of life conflicts (EOL conflict) evolve and are resolved in a day or two. Others unfold over weeks, or even months in some cases. These conflicts are not just an issue for Intensive Care Units (ICU) involving decisions around use of 'high-tech' treatments, although these settings have produced several high profile cases in NSW.[2,3,4] However, most of the population die outside of intensive care units and thus treatment limitation decisions made across a range of clinical settings have the potential for conflict. The majority of individuals however die within hospital and hospice settings in NSW. While advance care planning discussions are essential in community and primary care settings, most disputes about use of life sustaining treatments at EOL still predominantly play out in hospitals. This Report and its recommendations focus largely on the hospital setting. A consequence of failing to reach consensus[5] is an escalation of the treatment limitation decision from the usual, purely private paradigm to unit or institution management, or even beyond to the full public

scrutiny of the Health Care Complaints Commission, tribunals and Courts.

Wherever EOL conflict occur, they need to be managed in a timely manner which focuses on the **best interests[6] and best outcome for the patient**. Delays and protracted discussions with family may defer decision-making for the patient and prolong the patient's discomfort, distress or pain in the dying phase of their illness.

EOL conflict in NSW appear to be broadly generated by problems with ineffective communication, disparate expectations, avoidance of EOL discussions, and time constraints. Other factors identified include missed opportunities for timely advance care planning discussions; risk management concerns; fragmentation of care and communication across multiple teams; emotional responses to loss and dying; and health professional and/or community misunderstanding about some ethical and legal issues related to end of life decisions. Resolving EOL conflict in cross-cultural settings can raise additional complexities around cultural assumptions and taboos associated with death and dying. 'Transition times' appear to be a high risk time for EOL conflict, for example where a patient moves from paediatric-adult care, acute-palliative care, or to onset of terminal care. Importantly, there needs to be better recognition of when patients enter the dying phase in their illness trajectory than currently occurs. Appendix 1 provides an overview of factors predisposing to conflict in end of life decisions.

Most conflicts are probably anchored in some form of communication breakdown. The most effective strategies for preventing and managing EOL conflict are therefore likely to be those that address this aspect of clinical practice. Allowing families sufficient time and holding iterative, open discussions with them where patients can no longer decide for themselves remain the critical elements in minimising and resolving these disputes. Well planned and managed family conferences emerge as a powerful mechanism for generating understanding and agreement

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1 Winter L, Mockus Parks S. Family Discord and Proxy Decision Makers' End-of-Life Treatment Decisions. Journal of Palliative Medicine 2008;11(8):1109-1114.
2 Northridge v Central Sydney Area Health Service [2000] NSWSC 1241 revised – 17/01/2001
3 Isaac Messiah (by tutor Magdy Messiha) v South East Health [2004] NSWSC 1061 (11 November 2004)
4 Krommydas v Sydney West Area Health Service [2006] NSWSC 901
5 See Glossary

6 See Glossary

about EOL decisions. Efforts to resolve disagreement and forge a clinical consensus between clinical teams before approaching families to discuss limitation of life-sustaining treatment are essential and could be improved in current practice. Some EOL conflict will nonetheless require strategies beyond these mainstays of consensus-building. This report outlines a number of options. Figure 1 outlines the process proposed by the Working Group for resolving EOL conflict in cases where the patient does not have decision-making capacity.

Most of the measures likely to yield the greatest improvements are already in place in the NSW public health system but need strengthening and wider adoption. Importantly, there are no 'magic bullets' in this difficult area of clinical practice. The more contentious options examined by the Working Group have low levels of evidence as to appropriate modelling and efficacy in this specific area, despite their use in some overseas jurisdictions. In particular, this applies to 'mediation' and use of clinical ethics committees or ethics case consultation. These are discussed in this Report and recommendations are made that support further investigation of appropriate models and their evaluation in practice. Overall, the Working Group found there is relatively little overseas and almost no local evidence around 'what works' with EOL conflict.

The Courts and tribunals will always be needed to resolve a very small proportion of intractable EOL conflict. This is however, a rare occurrence, especially when considered in relation to the level of activity around end of life decisions in the NSW public health system. While it is difficult to estimate accurately, there are probably hundreds of EOL decisions made every day across care settings in NSW. What is apparent is that there is widespread apprehension amongst health professionals about becoming involved in Court processes. This is despite less than 10 end-of-life decision-making cases requiring ruling by the Courts (excluding Guardianship Tribunal) or being subject to subsequent compensation litigation over the last decade in NSW. That these 'high level' EOL conflict are so infrequent is testament to the skill and sincere efforts of health professionals as well as the practical wisdom of families. Nonetheless, these cases appear to have generated real fears.

What is clear is that health professionals, including senior clinicians with primary responsibility for negotiating a consensus decision, need support in these often intensely difficult situations. Mentoring, debriefing and other support processes are recommended.

It is also clear that resolving these conflicts can be time consuming. Skilled clinicians holding iterative discussions with families, particularly where patients are incapable, that are coordinated to involve the relevant health professionals is the key to doing this well. However, this takes time and time is a precious resource in the prevailing health system climate. This has implications then for appropriate clinical coverage to ensure that clinicians can be freed from other clinical responsibilities. Only when sufficient time is allowed and these discussions are widely valued will they become prioritised in daily practice.

Health professionals across care settings identified the need for improved access to and availability of palliative care services in NSW as important for transitioning care and expectations about that appropriately. At the same time, there is need for continued efforts to dispel the notion that palliative care is limited to the terminal phase of life. Referral to palliative care still comes with a stigma for a proportion of patients and their families.

Complicating matters is that there is no systematically collected data about EOL conflict in NSW, and possibly other Australian jurisdictions. In particular, the Working Group was unable to obtain precise data on the conflicts taken to the NSW Health Care Complaints Commission or NSW Guardianship Tribunal, or on the outcomes of mediations and rulings made by them. Practice improvement critically hinges on availability of data about both 'low' and 'high' level EOL conflict and recommendations have been made for evaluation and routine data collection. Despite an unclear picture about the current incidence and full complexion of EOL conflict in NSW, these conflicts do matter. The Working Group recognised significant adverse impacts at a number of levels affecting patients, families, health professionals and the broader health system.

Recognising the limitations in local empirical data, this Report has been developed based on Working Group members' expertise, and their consideration of the literature in this area, as well as the responses received during project consultations.

The way forward

Establishment of this project and the findings of this Report are not a reflection that crisis exists in end of life decision-making in NSW. The objective of this Report is principally to improve decision-making and care at the end of life in ways that are consistent with the values that underpin our public health care system. This is not a guideline, but rather a blueprint that outlines areas warranting further investigation, strengthened practice or new initiatives required to meet that goal.

This CRELS Working Group Report to NSW Health outlines 31 recommendations. Some recommendations simply affirm current practice. Others are practical initiatives that can be initiated in the short term and which fall within the remit of NSW Health. Others require referral to and consideration by other agencies and bodies. Finally, some call for long-term cultural and system changes.

The Working Group's recommendations are detailed in Section 5 Responses and Recommendations. By way of summary, these are grouped below according to projected development and implementation timeframes.

Short term

- Recognise and reinforce that time and further discussion with families remains the mainstay of EOL conflict management (Rec 5.1.1).
- Develop best practice advice on managing EOL family conferences & incorporate this into current and future EOL care pathways or other EOL care plans (5.2.1, 5.2.2).
- Introduce EOL conflict audit in NSW Intensive Care Units and other clinical areas where EOL decisions are frequent (5.10.1, 5.10.2) to enable evaluation of EOL conflict locally.
- Develop an EOL conflict 'tool kit' for managing an escalating dispute targeted at senior Area administration level (5.9.1).
- Develop/promulgate a tool to better identify the patient's substitute decision-maker while the patient still has decision-making capacity (5.5.3).
- Clarify roles of DOH Legal Branch and the Guardianship Tribunal in EOL conflict with clinicians and administrators (5.7.4, 5.8.1.1).
- Develop educational material for a lay audience on selected EOL issues (e.g. use of cardiopulmonary resuscitation, or use of artificial hydration & nutrition) or refer development of same to an appropriate national body (5.7.1, 5.7.2).

- Develop standards and an agreed process for sourcing and resourcing second medical opinion as an adjunct to resolving EOL conflict (5.3.1).

Medium term

- Prioritise communication skills training and related supervision/mentoring for doctors at under- and post-graduate levels (5.6.2).
- Establish routine data collection on EOL conflict by relevant agencies (5.10.3, 5.10.4).
- Consider implementing existing tools to better delineate patient demographics which predict where death is likely in next 6-12 months so as to target anticipatory discussions about dying (5.5.3).
- Encourage greater involvement of senior social workers & nurses in identifying the need for EOL discussions between the treating teams and families (5.2.3).
- Encourage development of local policies and procedures within Area Health Services to mentor and support health professionals involved in EOL conflict (5.8.4.2).
- Determine applicability and feasibility of 'facilitated negotiation' as applied to EOL conflict in NSW, in consultation with the NSW Health Care Complaints Commission (5.8.2.1) and evaluate a suitable model in practice.
- Minimise barriers to appointment of enduring guardians (5.5.1).
- Improve communication and coordination of EOL care in the transitional setting, in particular for paediatric patients transitioning to adult settings (5.5.5).

Longer term

- Improve access to social workers in areas of need to facilitate family conferences & follow up (5.2.4).
- Improve utilisation of, and access to interpreter services in EOL settings in NSW public health organisations (5.4.1).
- Support the development of communication skills training programs targeted at medical specialties with high clinical interface with EOL decisions (5.6.1) and the incorporation of these programs into continuing education in the postgraduate and professional setting.
- Support cultural competency training for health professionals in settings with significant CALD populations and frequent EOL treatment decisions (5.4.2).
- Establish transparent processes in Area Health Services for managing ethical dilemmas in clinical practice, including EOL conflict (5.8.3.1).

- Clarify the role and legal authority of the person responsible when a decision to focus on palliative care is needed on behalf of a patient lacking capacity (5.5.4).
- Recognise, support and refer the following priorities for an Australian EOL decision-making research agenda (5.4.10):
    - Establishing local best practice in managing family conferences in EOL settings;
    - Effectiveness of second medical opinion as an adjunct in resolving EOL conflict;
    - Auditing the NSW experience in cross-cultural misunderstandings in EOL settings;
    - Effectiveness of current legal mechanisms for resolving EOL conflict; and
    - Use and effectiveness of ethics case consultation in NSW public health institutions where this is current practice (5.8.3.2).

Figure 1: Resolving EOL conflicts where the patient has no decision-making capacity

This flow chart summarises the process recommended in this document. It expands on the process described in the flow diagram in NSW Health *Guidelines for end of life care and decision-making* (Appendix 2) at the point where conflict has been identified.

- Agreement sought, preferably consensus, between clinical teams re ongoing management & potential recommendation to withhold life-sustaining treatment (See 4.1)
- Assess if patient wishes known: written ACD/ACP, verbally expressed

- Social work
- +/- Chaplain
- +/- Interpreter assistance

Family conference* regarding decision to withhold/ withdraw life-sustaining treatment: note role of substitute decision-maker (SDM) (person responsible incl. enduring guardian) *See section 5.2

Consensus
- Enact agreed care plan re withdrawal or non-provision of unwanted or uwarranted life-sustaining treatment
- Ongoing support for patient & family
- Support for clinicians involved, especially where care has been protracted

Medical recommendation in favour of life-sustaining treatment refused by person responsible

No consensus

- More time
- Further discussions by family conference

Consider early application to Guardianship Tribunal* for consent or guardian appointment where patient condition or dispute dynamics warrant this (*not applicable for children)

No consensus

- Facilitate obtaining independent expert second medical opinion *See section 5.3

No consensus

- Notify senior hospital administration if not done so already
- Seek legal advice from DOH Legal – request triaged via senior Area administration
- Debriefing/mentoring support made available for clinicians involved
- Approach Clinical Ethics Committee/seek advice via clinical ethics case consult, where available

Apply Guardianship Tribunal
- Prepare for hearing & attend
- Continue discussion with SDM & family during and after Tribunal decision
- Enact care plan to comply with Tribunal decision

No consensus

Apply Court
- Continue discussion with SDM & family during and after Court decision
- Comply with decisions of the Court with advice DOH Legal
- Enact care plan

SECTION 2

Introduction

'End of life' decisions about withholding or withdrawing life-sustaining treatment in dying patients are a daily occurrence in hospitals and other care settings across NSW. These decisions may be made days, weeks or even months before a terminal event in patients with serious or life-threatening illness. Most of these are managed well and result in a ready agreement between the patient and/or their family and the treating clinical team as to the best goals of care and related treatments. The fact that these, sometimes distressing, decisions result in relatively infrequent conflicts is a testament to the skill and sincere efforts of health professionals as well as the practical wisdom of families.

Some end of life conflicts (EOL conflict) will be unavoidable, even in the best possible health system and with impeccable negotiation on the part of health professionals involved. However, a proportion may be avoidable altogether or more readily resolvable, given that a number of potentially remediable elements may co-exist in these disputes, often around miscommunication.

How often do conflicts in end of life decisions occur? Unfortunately, there is no systematically collected data in NSW, or probably in other Australian jurisdictions. The NSW Health Care Complaints Commission deals with a very small proportion of EOL conflict as part of their complaints handling process, however the Working Group was unable to identify any existing data sources regarding incidence or nature of EOL conflict in the NSW public health system.

Nonetheless, significant adverse impacts associated with these disputes were identified:

- Patients are affected where prolonged and avoidable pain and suffering accompany extended use of life-sustaining treatments about which agreement cannot be reached.
- Families are affected in living with the death of a loved one, let alone dealing with the intense emotions associated with conflict around a prior decision to withhold or withdraw treatment. Sometimes this effect is profound and long-lasting – for a life time in some cases.

- Health professionals are affected. These conflicts generate significant emotional and psychological stress, possibly a sense of having failed families and/or patients, and searching questions about what could have been done differently or better. Protracted, unsuccessful negotiation about an EOL decision can generate genuine moral distress in attending health professionals (HPs) where care must continue to be provided till a resolution is found.[1,2] Where this continues for weeks or in some cases months, this may be far beyond the point at which HPs believe the patient is benefiting from that treatment. Furthermore, the HPs may believe that continued treatment is harming the patient, or that continuing treatment in such cases means denying treatment to others who may derive more benefit. Unfortunately, in some cases in NSW these conflicts have been accompanied by grave physical and emotional threats directed at the health professionals involved.
- Finally, the broader health system is affected. There appears to be a widely held apprehension of becoming embroiled in Court processes and possibly a reluctance to escalate conflicts where that may result. This is despite less than 10 involving EOL conflict reaching the Courts (excluding the Guardianship Tribunal) in NSW over the last decade. Nonetheless, this fear may be influencing a defensive risk management approach to decisions at a clinical and institutional level.

It is known that EOL conflict occur in NSW in several settings: between a competent (or border-line competent) patient and their family and/or treating clinician/s; within families; within and between disciplines in health care teams; and between the treating team and the family of a patient who has lost decision-making capacity. The Working Group considered issues related to all these contexts but with most attention to the latter.

1   Georges JJ, Grypdonck M. Moral problems experienced by nurses when caring for terminally ill people: a literature review. Nursing Ethics 2002;9(2):1550-178.
2   Davidson JE, Powers K, Hedayat KM. et al. Clinical practice guidelines for support of the family in the patient-centred intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. Crit Care Med 2007;35(2):605-622.

The following are three examples of poorly resolved
end of life conflicts.

Case example 1

Mary is an 82 year old woman who is admitted in advanced
renal failure. She has diabetes and ischaemic heart disease
and while receiving haemodialysis suffers a right ventricular
myocardial infarction. She has a stent and a temporary
pacemaker inserted and is stabilised in CCU. Several days
later while having a permanent pacemaker inserted, she
suffers a stroke. Although she partially regains
consciousness, she is left with difficulty swallowing and has
a nasogastric tube inserted. Her renal physician is of the
view that dialysis should not be continued at this point and
that comfort care measures should now become the focus.
He raises this with the treating cardiologist who disagrees
and is adamant that maintenance dialysis should continue
and that CPR should be provided if she deteriorates. The
cardiologist emphasises her stable cardiac function in
conversation with Mary's family.

Case example 2

David is an 8 year old child with a terminal brain tumour.
He has been sick for a year intermittently, having gone
through two operations and a number of rounds of
chemotherapy. He has now been admitted to hospital with
increasing drowsiness, loss of appetite and difficulty
walking. His parents, Helen and James, want all treatments
provided to David, including resuscitation in the event of
respiratory and/or cardiac arrest. His treating doctors meet
with them and advise them against resuscitation, saying
that they believe he is now dying.

David's condition continues to deteriorate over the next
several days and he is now unconscious with laboured
breathing. James and Helen have met with the treating
doctors each day but continue to insist on resuscitation
and that, if successful, David should be admitted to the
ICU and ventilated. They say that they are not ready to
accept that he is dying and that a miracle might occur to
cure the cancer.

Case example 3

Brett is a 29 year old man who has sustained severe head
injuries and a high cervical spinal injury in a motor vehicle
accident. He is unconscious, sedated and on a ventilator
in the intensive care unit (ICU). Over the next 24 hours the
pressure inside his brain rises to very high levels.

The following day the treating intensive care doctor holds
a family conference with his parents and brother advising
them that Brett's condition is worsening and that he
expects further deterioration. His family is understandably
upset and a plan is made to continue treating and
observing him over the next 24 hours. Social work and
chaplaincy support are provided.

Two days after his admission to ICU, another family
conference is held where the ICU doctor informs the family
that, given his condition and prognosis, consideration
should now be given to withdrawing the ventilator and
other life-supports. The family is advised that all doctors
involved in Brett's care (neurology, spinal and intensive care)
agree that it now appears likely he will not survive, even
with all aggressive treatment provided. The family is very
distressed and his father, Harry becomes angry and hostile
towards the doctor. A decision is made to continue
treatment for another 48 hours to give the family more
time to come to terms with the situation.

Daily family conferences are held over the next 6 days but
no consensus is reached and Brett's condition shows no
signs of improvement. Over that time, the treating doctors
consult spinal and intensive care specialists beyond the
hospital who agree that death is highly probable and, if he
survives, he will likely be a high quadriplegic in a comatose
state. This information is conveyed to the family. Harry
remains aggressively opposed to medical opinion and
makes threats about what he'd do to himself and treating
health professionals if treatment is withdrawn.

SECTION 3

Background

NSW Health recognised the complex challenges in end of life decision-making in the *Guidelines for end of life care and decision-making*[1] in 2005. Those guidelines provide a policy framework and recommended process for health professionals to use in reaching decisions collaboratively with patients and families about use of life-sustaining treatments at the end of life. 'Consensus', though not defined in those guidelines, is taken in this document to mean a collective decision accepted and supported by all engaged stakeholders, even where their own preferences may differ. Those guidelines include reference to a range of options for resolving disputes around these decisions:

- Time and repeat discussion
- Second medical opinion
- Time limited treatment trial then review and renegotiation
- Facilitation (by an independent third party)
- Patient transfer by agreement to a willing care provider
- Applying to the Guardianship Tribunal for guardianship orders (in some circumstances)
- Legal intervention

Since release of the *Guidelines for end of life care and decision-making* the NSW Health Department recognised that more detailed exploration was appropriate as to the cause, prevention and management of end of life conflicts as they occur in the NSW public health system. Some of the above strategies receive more detailed attention in this Report.

In addition, since 2000 there have been a number of high profile legal cases involving EOL conflict in paediatric and adult settings here and overseas that have illuminated the issues and concerns with EOL decision-making in clinical care settings.[2,3,4,5,6,7,8]

3.1 Literature review

In preparation for this project, the Department commissioned a literature review[9] through the Sax Institute. The Simpson Centre for Health Services Research at University of NSW was engaged to produce the review. Some 192 citations were reviewed and collated. That literature review "*Conflict Resolution in End of Life Treatment Decisions: an 'Evidence Check' Review*" can be accessed on the NSW Department of Health website at: www.health.nsw.gov.au/resources/ethics/research/review _conflict_resolution_pdf.asp

The review outlined potential interventions where some evidence of efficacy exists. Importantly, it identified a general lack of empirical data to support most widely used or recommended interventions to minimise and manage EOL conflict. There was virtually no Australian research data in this area. This probably reflects that managing conflict does not readily lend itself to rigorous testing using conventional research methodologies but raises difficulties for local practice improvement. However, in summary, that review identified potentially useful strategies as being:

- "Greater uptake of advance care planning and clear access to such plans;
- Communications training for health professionals & standardised approaches to family conferences;
- Earlier palliative involvement, and development and roll-out of state-wide 'end of life' care plans;
- Early identification of patients with a high likelihood of dying;
- Ethics consultations and their use and limitation;
- External mediation by expert, independent mediators;
- Legal avenues for resolution, including Tribunals; and
- Commentary as to engaging society about options and expectations around end of life issues."[10]

1   NSW Health *Guidelines for end-of-life care and decision-making*, March 2005
2   *Northridge v Central Sydney Area Health Service* [2000] 50 NSWLR 549
3   *AN NHS Trust and MB and ORS [2006] EWHC 507 (Fam)*
4   *Hunter Area Health Service v Marchlewski & Anor [2000] NSWCA 294 (26 October 2000)*
5   *Inquest into the death of Paulo Melo* [2008] NTMC 080
6   *Isaac Messiah (by tutor Magdy Messiha) v South East Health (2004) NSWSC 1061* (11 November 2004)
7   *Krommydas v Sydney West Area Health Service* [2006] NSWSC 901
8   *Wyatt [No3] [2005] EW HC 693 (Fam) 21 April 2005*

9   Hillman K. and Chen J. (2008), Conflict resolution in end of life treatment decisions: An evidence check review brokered by the Sax Institute for the *NSW Department of Health*, NSW Department of Health, 2008.
10 Hillman K, Chen J. op cit. 2008

Over the last 2 decades, the US experience in policy development in this area has provided some salutatory lessons. The first generation of policy in that country and ethical discourse at that time was characterised by significant, but unsuccessful attempts to define 'medical futility' on various clinical criteria.[11,12,13,14,15] As these disputes are often about family demands for doctors to 'do everything' but which health professionals believe to be 'futile', it was hoped that developing medical futility guidelines would allow health professionals to discern which treatments were futile, and which may then be lawfully ceased, even or especially in the face of family demands.

The second generation response over the last 5-10 years has shifted to a more procedural approach where 'fair process' guidelines have empowered some hospitals, through their clinical ethics committees and in some states with legislative support, to decide whether interventions demanded by families were futile.[16,17] These processes include recourse to the Courts where dissent persists. Numerous problems exist with these approaches[18] but a fundamental problem is that in both the US and Australia, there is ongoing debate with no national consensus about what constitutes 'beneficial' treatment, its limits, and thus futile treatment.

There is now an emerging focus in the US on better communication and shared decision-making 'at the bedside'[19,20] as the way to resolve EOL conflict. While a small proportion of cases will always need resolution in the Courts, this emphasis in managing end of life conflicts is already part of the landscape of clinical practice in EOL settings in Australia and continues to be strongly endorsed in existing NSW Health policy.

Based on the background, NSW Health decided to review its strategies to reduce the risk of conflict and to optimise patient and family and staff satisfaction around this critical end of life decision making. This "Conflict Resolution in End of Life Setting" Project included the establishment of an expert working group.

3.2 Conflict Resolution in End of Life Settings Project: Terms of Reference

The NSW Health *Conflict Resolution in End of Life Settings* (CRELS) Working Group was constituted to:

1. Consider issues in relation to conflict in end of life decision-making and its resolution including:

■   Relevant differences as to the incidence and nature of EOL conflict between paediatric and adults settings;
■   Available evidence regarding contributing factors including cultural, religious and socioeconomic factors;
■   Available evidence regarding efficacy of preventative and direct interventions;
■   Potential applicability of these or other measures in the NSW health system; and
■   Identification of areas where further consultation and investigation may be required.

2. Develop recommendations, and their prioritisation, regarding appropriate strategies/interventions to address conflict in end of life settings in the NSW public health system.

3.3 Conflict Resolution in End of Life Settings Project: Process

The CRELS project was established in March 2009 including an expert Working Group (membership at Appendix 3). Nursing and community perspectives were sought through other mechanisms rather than nominating a single representative to the Working Group. This approach was adopted because the spectrum of care settings in which end of life conflicts occur meant that garnering a range of nursing and community perspectives was needed.

The Working Group's deliberations were assisted by a series of consultation meetings between Working Group members, Secretariat and a range of health and other professionals and community members. An independent facilitator was engaged to run the community and nursing

11   Schneiderman LJ, Jecker NS, Jonsen AR. Medical Futility: Response to Critiques. *Annals of Internal Medicine* 1996;125(8):669-674.
12   Youngner SJ. Medical Futility. *Critical Care Clinics* January 1996;12(1):165-178.
13   Caplan AL. Odds and Ends: Trust and the Debate over Medical Futility. *Annals of Internal Medicine* 1996;125(8):688-689.
14   Lantos J. When parents request seemingly futile treatment for their children, *The Mount Sinai Journal of Medicine* May 2006;73 (3):587-589.
15   Helft PR. et al.The rise and fall of futility movement. *NEJM* July 2000;343(4):293-297.
16   Okhuysen-Cawley R. et al. Institutional policies on determination of medically inappropriate interventions: Use in five pediatric patients. *Pediatric Critical Care Medicine* 2007;8(3):225-230.
17   Truog RD. Tackling Medical Futility in Texas. *NEJM* 2007;357(1):1155-1157.
18   Wojtasiewicz ME. Damage Compounded: Disparities, Distrust, and Disparate Impact in End-of-Life Conflict Resolution Policies. *American Journal of Bioethics* 2006:6(5):8-12.
19   Burns PB, Truog RD. Futility: A Concept in Evolution. *Chest* December 2007;132 (6):1987-1993.
20   Davidson JE, Powers K, op cit. 2007

meetings. The Working Group directly met with, or received feedback from:

- Senior social workers from Liverpool, Westmead and Westmead Children's Hospitals and elsewhere in SSWAHS, in particular in relation to issues with patients or families from culturally and linguistically diverse (CALD) communities;
- Doctors who responded to open invitation via GMCT networks. Specialist expertise included disability care, transitional care, renal, respiratory, rehabilitation medicine and geriatrics;
- Professor Malcolm Fisher AO, Clinical Professor in Intensive Care Medicine in the Departments of Medicine and Anaesthesia at the University of Sydney.
- Nurses in response to open invitation extended via the Office of the Chief Nursing Officer to all Area Directors of Nursing & Midwifery. More than 40 nurses responded, principally Clinical Nurse Consultants and Nurse Managers with expertise in palliative care, chronic and aged care, stroke care, dementia care, transitional care, discharge planning, acute medical and surgical care, ICU, and renal services;
- Associate Professor Cameron Stewart, Director of the Centre for Health Governance, Law and Ethics, Sydney Law School, University of Sydney;
- The Pam McLean Communication Centre, Northern Clinical School at University of Sydney in relation to medical communication skills training;
- Academics and interpreters from the Interpreting and Translation College Research Group, School of Humanities and Languages, University of Western Sydney (Bankstown) in relation to medical interpreting; and
- A small group of community members who volunteered in response to invitation via the 'Family Advisory Group' at Children's Hospital Westmead, the 'Parent and Consumer Council' at Sydney Children's Hospital, and SESIAHS Advance Care Planning Group and related community network.

These informal targeted consultations, while raising recurring themes and concerns, were not a proxy for qualitative research and must therefore be considered accordingly. In particular, it was not possible to comprehensively elicit 'community perspectives' about EOL conflict within the project's resources. Those perspectives, especially those within culturally and linguistically diverse (CALD) groups, warrant further investigation.

The CRELS Report was disseminated widely from May to June 2010 for comment. Forty nine responses were received. See p.55 for Consultation Summary.

Factors Contributing to End of Life Conflicts

Broad ranging factors, many of them inter-dependant, were identified as contributing to end of life conflicts in NSW. These are schematically represented in Appendix 1. Some of these are societal issues beyond the health system and, as such, are difficult to influence and change. Others relate to prevailing norms, practices, systems and values within our health system as well as individuals' responses to dying, grief and loss. It is probable that multiple factors co-exist to shape and drive these disputes whenever they occur.

On examining this area, it became clear that these conflicts illuminate many of the challenges in providing end of life care generally, for example the need for sound approaches to substitute decision-making. Moreover, these conflicts seem to offer a window into many broader health system concerns beyond EOL care, for example challenges in achieving effective communication between care teams, continuity of care across settings, shifting roles and responsibilities of health professionals, cultural competency concerns, and sometimes unrealistic community expectations about what medicine can achieve and how these play out in clinical interactions.

The Working Group's deliberations were prefaced with the assumption, accepted in most Western health systems in regards to end of life care, that withholding or withdrawal of life-sustaining treatment is a legitimate course of action (subject to the particulars of each case). This may not be shared by all cultures or religions.

Lack of local data about end of life conflicts

A preliminary issue for the Working Group was the inability to quantify through any existing NSW data collections how often EOL conflicts occur overall, the severity of them, what proportion become 'high level' conflicts requiring interventions beyond direct negotiation between doctors and families, or the dynamics involved.

Defining end of life 'conflict'

Another preliminary issue was how to define EOL 'conflicts'. This Report has adopted a broad definition of EOL conflict

being 'where disagreement has occurred as to the goals of care or treatment decisions and where such conflict is not resolved by usual recourse to time and further discussion'. Potential ambiguities in how much time needs to lapse and how many repeat discussions should transpire before an impasse with a family should be defined as a 'conflict' may complicate potential future data collection in this area.

Use of the term 'family'

Frequent reference is made in this Report to 'family' in decision-making conflicts. This is not to discount the primacy of patients deciding for themselves about the use of life-sustaining treatments at the end of life when they have the capacity to do so.[1] Conflicts do arise in this situation, but are rarer than where the person can no longer decide and their family takes on the mantle of deciding on their behalf in conjunction with the treating team. The term 'family' is defined in the Glossary and is not meant to be limited to blood relatives but also includes those individuals that the patient considers family or those that the patient would wish to be involved in decision-making about their care. This is distinct from the consenting role of the 'person responsible'.

Conflict between the patient and treating doctor/s

Conflicts about end of life decisions between the patient and his or her treating doctor/s are less frequent than those that are the primary focus of this Report, those being between an incompetent patient's family and the treating team.

Where conflict arises in the care of terminally ill patients it is critically important to establish whether the patient is competent as it is widely recognised in ethics, law and clinical practice that a patient with capacity may make treatment choices to refuse or to request any therapy, consistent with his or her own values, even where these choices and values differ from those of the treating team. While the law assumes that adult patients are competent to make decisions regarding their own care, where there is any

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1   NSW Health *Guidelines for end-of-life care and decision-making*, March 2005

doubt that the patient has sufficient decision-making capacity, their decision-making capacity should be assessed according to established guidelines and the results of this assessment documented in the patient's records.[2]

In the setting of critical illness, the treating clinician should consider that some chronic or acute illness such as sepsis, sedative drugs, delirium, pain, mental illness, or dementia might adversely impact a person's decision-making capacity. Where decision-making capacity is impaired, reasonable efforts should be taken to maximise his or her capacity to participate in decisions. Provided this is not harmful to the patient, this might include treating any active infections, providing adequate analgesia, ceasing any medications that may be impairing the patient's decision-making capacity and conducting discussions in a quiet and calm environment. Such efforts may improve the patient's ability to participate in discussions."[3]

4.1 Conflicts within the Health Care Team

Conflicts about withholding or withdrawal of life-sustaining treatment can occur within and between treating teams and may be generated by several factors including:

■ Genuine clinical disagreement about prognosis, chance of treatment 'success', and how that should be defined;

■ Cross-cultural differences between clinicians from different cultural backgrounds that may influence willingness or unwillingness to support treatment limitation in their patients;

■ Potential reluctance to have 'difficult discussions' about dying as a result of differing personal communication styles and skills;

■ Personal (perhaps religious) values and beliefs that may influence a clinician's 'ethos' of end of life care; and

■ Different 'cultures' within medical specialties that may generate divergent views about aggressive treatment and its appropriateness at the end of life.

Especially where there are multiple teams involved, it is critical to make efforts to resolve disagreement about a patient's prognosis and appropriate EOL care, and preferably achieve a clinical consensus, before opening a discussion with a patient's family about limitation of life-

sustaining treatment. There is a tension that emerges between, on the one hand, not stifling genuine clinical disagreement between clinicians and, on the other, the need for all treating doctors to abide by a reasonable clinical consensus and not give mixed, even contradictory information to a family. Providing specialty-specific information in isolation from other treating clinicians runs this risk. Getting prognostic agreement however, is not always easy. Prognostication is not a precise science, even if better tools were available to aid in the task.

As in any inter-personal disagreement when individuals are challenged, personal responses can close communication down, making intra-team EOL conflict sometimes as difficult to negotiate as it can be with families.

Even where a clinical consensus has been established about an appropriate direction of EOL care, this is not the same as certainty of clinical outcome. This can present challenges in negotiating decisions with families[4] who will often, understandably, seek assurance and certainty that survival and recovery is not possible. An important demarcation in this Report is separating a second opinion sought between colleagues to clarify the prognosis for treating clinicians from a second opinion sought to resolve conflict with families. This use of a second medical opinion in the latter circumstance as a 'circuit breaker' is discussed further in Section 5.3.

4.2 Communication problems

Even impeccable efforts at negotiation may sometimes fail & there will be a small proportion of cases where, despite best efforts, the conflict will escalate, potentially to the Courts. However, communication breakdown is probably the most important contributing factor in EOL conflict, especially conflicts between the treating team and family. It can be both the precipitating event for a conflict, or the final pathway through which a loss of trust in those trying to negotiate an EOL decision is expressed by a family. Where trust is lost, the likelihood of negotiating an agreement rapidly diminishes.[5]

The applicability of mediation, in particular a 'facilitated negotiation' model, was considered in this context, including where communication has significantly broken

2 Attorney General's Department, NSW Government, *Capacity Toolkit: Information for government and community workers, professionals, families and carers in New South Wales*, June 2009.

3 NSW Health GL2008_018, *Decisions relating to No Cardio-Pulmonary Resuscitation Orders*, 2008

4 Aldridge M, Barton E. Establishing Terminal Status in End-of-Life Discussions. *Qualitative Health Research* Sept 2007;17(7):908-918.

5 Caplan AL. Odds and Ends: Trust and the Debate over Medical Futility. *Annals of Internal Medicine* 1996;125(8):688-689.

down. There are numerous models of mediation,[6] many of which are unsuitable to this context. The use of mediation in EOL decisions poses some specific difficulties compared to its use in other areas, however facilitated negotiation warrants further investigation, trialling and evaluation as an adjunct to resolving EOL conflict. This is discussed in more detail in 5.8.2.

A number of issues relating to communication were identified and are discussed in the following sub-sections.

4.2.1 Impact of early miscommunication

An early misunderstanding, a personality clash, or a previous bad experience with the health system (their own or someone else's) can generate early mistrust in patients and families. This can be exacerbated as health professionals sense tension or hostility and become reluctant to communicate with that family, further fuelling communication difficulties. Establishing good communication early is important.

4.2.2 Discomfort with difficult discussions

There can be avoidance of difficult conversations where anger or strong opposing views are anticipated, where there has been prior disagreement, and especially if health professionals feel inadequately skilled in having those conversations. This may further fuel tensions and mistrust.

4.2.3 Subliminal messages

Subliminal messages are present in all communication, including between health professionals and families. Where parties (either health professionals or families) become frustrated, appear to have stopped listening, or have become intransigent when a consensus decision remains elusive, despite best efforts at open dialogue, this will impede reaching a consensus decision.

4.2.4 Mixed messages to families from clinical teams

Minor variations in how a patient's prognosis is described to a family may erroneously sound like differences in clinical opinion. Certainly real divergence in clinical opinion between treating specialists has the potential for confusion on the family's part. When this occurs, many families will understandably hang on to the most positive clinician's viewpoint. These mixed messages, intended or otherwise, during incidental conversations or during formal family conferences, were thought to be a common contributor to

EOL conflicts. Where language is 'softened', for example in use of euphemisms to lessen distress or otherwise create a positive sense from information even when its bad news, this can be misinterpreted by patients or families as different diagnostic/prognostic information.[7] That health professionals 'sing from the same song sheet' when discussing EOL decisions with families was widely supported.

In addition, social workers and nurses play an important role in supporting and updating families and also monitoring between family conferences as to that family's understanding and levels of agreement. Nurses' involvement in EOL discussions is sometimes compromised by workload commitments making them unavailable during ward rounds or other discussion time points. However, their involvement is important, among other reasons, to ensure that consistent information is given to families.

4.2.5 Family feeling pressured and/or rushed

There is probably a wide disparity between health professionals and the community perceptions as to what is a reasonable timeframe to allow a family to recognise that it might be time to cease life-sustaining treatment in a deteriorating or dying patient. Health professionals may seek very short timeframes for agreement to withdraw life-sustaining treatment, such as within 24 hours, even where the patient's clinical demise may still allow somewhat more time for decision-making with a family. Rushing individuals in this situation will likely add to anger, mistrust and may result in resistance. When families are fearful that withdrawal of life-sustaining treatment is being considered, and/or they feel they are being pressured for decisions, some will simply stop attending family conferences where these decisions might be made.

4.2.6 Individualised information

Provision of information that is meaningful and meets the needs of families to assist in decision-making around treatment limitation is important. Individuals may need additional, more detailed, or a different form of information and some vary in their preference for verbal, written or visual sources. It is therefore important to clarify with the patient and key family members about their preferences and to tailor information accordingly. If there are special preferences for information provision this should be clearly documented in the medical records and communicated to

6 Astor H, Chinkin C. *Dispute Resolution in Australia.* 2nd edition, Butterworths, Sydney, 2002

7 Philip J, Gold M. Uses and misuses of ambiguity: Misuses of ambiguity. *Internal Medicine Journal* 2005;35:629-631.

health professionals who are being consulted with regards the patient's care, especially those who are new to the case. This is especially important if these health professionals are being invited to attend family conferences or give second opinions.

4.2.7 Talking another language

This may take the form of using of overly technical language or medical jargon by health professionals. Vigilant use of plain English explanations about the patient's condition, prognosis and treatment options and checking and re-checking understanding are recommended. Where English is a second language and interpreters are required to negotiate an EOL decision, this will unavoidably complicate the processes. This is discussed further in the section 4.8 'Understanding Cross-Cultural Issues'.

Care should be taken to avoid terms that may be perceived as pejorative, for example terms like 'withdrawal of care', or 'harvesting' organs. The offence taken by some families may exacerbate an emerging dispute.

4.2.8 Need for improved communication skills

Decisions around life-sustaining treatment require excellent communication yet repeated findings in the literature[8][9][10][11][12] reveal physicians' communication skills in EOL settings are often sub-optimal. This was also reflected in local anecdotal reporting and suggests that there is room for re-prioritising the skill development in this area of clinical practice at senior levels within hospitals and in education and training through the professional colleges.

Skilled communication, especially in managing conflicts, comes with proper training and most importantly, mentored practice. Timing in one's professional development for acquiring such skills is also important. For example, a 'just in time' approach to training in how to 'break bad news' where skills are taught close to when they will be utilised in

practice is more likely to result in strong skills development and retention.

In relation to how doctors most effectively learn communication skills, it appears that individuals within different medical specialties approach & learn communication skills in surprisingly different ways. The use of training approaches tailored to clinical specialty and prioritised to those specialties with strong involvement in EOL decision-making may be an important, though longer term, strategy for improved EOL conflict management.

While individual initiatives by medical staff in some centres in NSW and elsewhere[13][14][15] are promising, overall there is a fragmented approach to communication skills training for doctors with limited financial and other support to make a significant impact across the range and number of medical clinicians in whom this training is needed. A national coordinated approach where relevant Colleges and Universities examine their curriculum and prioritise this area in their training programs should be considered. Under-graduate and post-graduate medical training programs should review their content to include appropriate levels of training in communication in end of life settings.

High level communications skills are also required from nurses and allied health professionals engaged in end of life decision-making processes. Similar concerns exist regarding training opportunities and supervision around communications skills for some of these disciplines. In general, social workers are well equipped in this role but are either unavailable or inadequately accessed for EOL negotiations in some settings in NSW.

4.3 Emotional responses to dying and loss

Strong emotional reactions are part of the terrain of negotiating and providing end of life care to patients and families. Normal responses to the impending loss of a loved one range from shock, distress, anger, fear, denial, hope, or sometimes all of these. Health professionals endeavour to help patients and families work with these feelings as death

8   Curtis JR, Engelberg RA, Wenrich MD, Shannon SE, Treece PD, Rubenfeld GD. Missed opportunities during family conferences about end–of-life care in the intensive care unit. *American Journal of Respiratory and Critical Care Medicine* 2005;171:844-849.

9   Burns CA, Byrne P, Kuhn S, et al. End-of-life care in the pediatric intensive care unit: Attitudes and practices of pediatric critical care physicians and nurses. *Critical Care Medicine* 2001;29:658-664.

10 Fallowfield L, Jenkins V, Farewell V, Saul J, Duffy A, Eves R. Efficacy of a Cancer Research UK communication skills training model for oncologists: A randomised controlled trial. *Lancet* 2002;359:650-656.

11 Back AL, Arnold RM. Dealing with Conflict in Caring for the Seriously Ill: "It was just out of the question." *JAMA* March 16 2005; 293(11):1374-1381.

12 Drew PJ, Cule N, Gough M, Heer K, Monson JRT, Lee PWR, Kerin MJ, Duthie GS. Optimal education techniques for basic surgical trainees: lessons from education theory. J.R.Coll.Surg.Edin. Feb 1999; 44:55-56.

13 Clayton JM, Hancock KM, Butow PN, Tattersall MHN, Currow DC. 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 Supplement, MJA* June 2007;186(12):S77-108.

14 Browning DM, Meyer EC, Truog RD, Solomon MZ. Difficult Conversations in Health Care: Cultivating Relational Learning to Address the Hidden Curriculum. *Academic Medicine* Sept 2007;82(9):905-913.

15 Corke C, Milnes S. *Communication for the intensive care specialist: Planning for effective, efficient and compassionate interactions.* Erudite Medical Books Ltd, United Kingdom

approaches. Sometimes these emotional reactions are perceived as that person being 'stuck' or in denial and repeated attempts may be made to get them 'unstuck' by reinforcing and repeating information about the patient's dismal prognosis. This can be counter-productive in some cases.

Sometimes these emotional responses overwhelm individual family members and can significantly contribute to an impasse about a decision to withhold or withdraw life-sustaining treatment, or indeed may drive a family member to escalate a dispute. These emotional responses may arise from pre-existing family dynamics. Some families have long-standing rifts, guilty distant relationships or entrenched family power plays that contribute to demands for, or disagreement about treatment.[16]These cannot be resolved during end of life conflicts. However, these dynamics must be recognised by health professionals, if not always openly acknowledged, and the emotional needs of adult family members addressed when negotiating EOL decisions. Sometimes psychopathology is responsible for persisting demands for continued aggressive treatment. In such cases, where demands for continued treatment are unreasonable and intransigent, it is ultimately in the patient's best interest to 'fast track' the dispute for timely resolution by the Guardianship Tribunal or the Courts.

Especially in situations with a new acute diagnosis or clinical problem, it is important to recognise how 'far ahead' the treating team may be in comprehending that death is imminent compared to parents and families. The importance of allowing families time, where at all possible, to absorb, question and begin to understand cannot be overstated. Provision of appropriate supports to families, such as social work, chaplaincy and others are vital.

Potential feelings of guilt associated with feeling responsible for a loved one's death by agreeing to withdraw or withhold life-sustaining treatment may make some families reluctant to do so. When discussing these decisions, the treating doctor should therefore take ultimate responsibility for the decision while explicitly acknowledging that this is being done in consultation with those parents or family. It is essential that families are not left to feel burdened that they have 'pulled the plug' on their loved one.

After death follow-up of bereaved families may assist some family members resolve emotional concerns related to

their loved one's death. This may reduce a proportion of complaints instigated after death.

4.4 Medical 'culture' and end of life decisions

A number of issues arose during consultation that could be characterised as part of the prevailing culture within some areas and aspects of medicine.

4.4.1 Death as failure of medicine

A sense of failure where death is imminent still often pervades medical culture. The fear of death is powerful in our community and doctors are habituated into making all therapeutic efforts, even as the chance of survival becomes vanishingly small. Openly acknowledging that someone is dying, despite intense efforts, and having explicit discussions about EOL decisions can generate discomfort for some doctors, can be accompanied by a sense that they are depriving patients or their families of hope, or that they have failed in the therapeutic relationship to be 'good' doctors. Too little discussion about treatment limitation too late in the illness course is one outcome. Significant cultural shift in medicine is needed to dispel the sense of death as failure. Sound discussion of EOL care can significantly enhance doctor-patient relationships.

4.4.2 Clinical leadership and EOL decisions

EOL decision making is a time that highlights the importance of competent and mature clinical leadership. In some cases, there is reluctance on the part of treating doctors to make strong treatment recommendations to a patient's family about not starting, or stopping life-sustaining treatments with concomitant shifting of responsibility for the decision to that family.[17,18] Fear of making strong recommendations may relate to:

- fear of escalation to the Courts where a family is insistent on aggressive treatment;
- fear of being seen as unfairly paternalistic;
- prognostic uncertainty;
- a genuine desire to negotiate decisions collaboratively because this is thought optimal; or
- combination of these.

Whatever the reason, this can lead to deferred decisions, unwarranted escalation of life-sustaining, and conflicts with

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16   Peisah C, Brodaty H, Quadrio C. Family conflict in dementia: prodigal sons and black sheep. *International Journal of Geriatric Psychiatry* 2006;21:485-492.

17   Murphy BF. What has happened to clinical leadership in futile care discussions? *MJA* 7 April 2008;188 (7):418-419.

18   Ashby M, Kellehear A, Stoffell B. Resolving conflict in end-of-life care. *MJA* 2005;183 (5):230-231.

families in negotiating cessation of life-sustaining treatment.

Intensivists and medical emergency response teams in some hospitals are now surrogate 'dying teams' in that they will often have the first discussion about the inevitability of death with the patient's family and treating team.[19] Clinical teams outside intensive care may not appreciate what intensive care can and might offer, or may simply wish to avoid difficult discussions with possibly hostile families. This may give relatives false hope. The open ended question, 'Do you want everything done?' should always be avoided. The expectations this creates can set the scene for conflict when the Intensivist must then either refuse admission, or negotiate subsequent withdrawal of treatment.

4.4.3 Initiating EOL discussion: not solely a doctor's role

Most discussions about end of life decisions are substantially medically-initiated, rather than by senior social workers or senior nurses who might also appropriately identify a need for such discussions. Time constraints with busy schedules and, in some cases, insufficient skill or aptitude may mean that some treating doctors are not always best placed to recognise the need for, or to initiate EOL discussions. It is probable that many families would like more and earlier opportunities for these discussions when sensitively introduced and a proactive role for senior nurses and social workers in this regard should be encouraged. In urgent and unplanned scenarios, engaging medical staff in this dialogue is recommended.

4.4.4 Quality of life judgements by health professionals

Health professionals have a moral obligation to be cognisant of the impact of treatments on their patient's life expectancy and quality of life. They must also consider and be respectful of the patient's own assessment of their quality of life. The NSW Ombudsman in 2005[20] raised concerns that, in some cases, health professionals' quality of life judgements regarding patients with chronic, degenerative disease and disability were being made or used inappropriately, for example in a discriminatory way, to withhold life sustaining treatments. Proper EOL decision-making should not be based upon assumptions about a person's quality of life, preferences for care and goals of treatment and should not lead to unilateral decision-making

by health professionals. Rather, it requires consideration of, and respect for the patient's own assessment of their quality of life; genuine efforts to understand the person's values and beliefs; appreciation of the patient's experience of illness[21] and the impact of this illness on those around them; and appropriate consultation with enduring guardians, family or carers as required.

4.4.5 Fostering a culture of care and compassion for health professionals

These disputes take their toll, both professionally and personally, on health professionals, especially where the conflict is protracted and, in particular, on those responsible for direct negotiations. A culture within health care institutions that is supportive of health professionals in these situations needs to be fostered. Institutional support mechanisms are needed and could take the form of:

- Individual de-briefing sessions using Area Health Service Employee Assistance Programs;
- Case conferencing meetings for staff directly involved in or affected by the case. These should be broadly inclusive and confidential, and may be run by Head of Department, and/or social work team, and/or palliative care team;
- Mentoring processes or other informal support systems between colleagues within or across institutions; and/or
- Clinical 'supervision' and support in very difficult cases.

On a more practical note, the institution may need to monitor the clinical caseload of individual health practitioners engaged in an EOL conflict scenario. Redirecting non essential activity to other clinicians within the service may itself be therapeutic for the engaged clinicians and lead to a better outcome in optimising time spent in communication with the family.

4.5 Difficulties predicting dying and conveying poor prognosis

Uncertainty is ubiquitous in medicine and the ability to predict the timing of death with great accuracy will probably always remain imperfect. However, an important contributor to EOL conflict is failure to recognise or 'diagnose' when someone has entered their dying

19   Hillman K, Chen J. op cit. 2008
20   NSW Ombudsman, *Report of Reviewable Deaths in 2005 Volume 1: Deaths of people with disabilities*, November 2006

21   Chochinov HM. Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *BMJ* 28 July 2007;335:184-187.

phase.[22,23] This inability to recognise dying and act on it with appropriate discussion and planning appear to extend from cases where health professionals would not be surprised if the patient were to die in the next 6-12 months, through to cases where death is imminent.

Successfully negotiating the use of life sustaining treatments will be impossible where a family, or worse yet the patient, does not appreciate that the dying phase has been entered. Only then can the family and the treating team change gears and move from curative to palliative phase care planning.

There is arguably an under-emphasis in both the medical curriculum and clinical practice on two important aspects of care being i) development of the skills necessary to come to a sound prognostic assessment of the patient's likely clinical course and risk of death, and ii) development of skills to communicate effectively with patients about their prognosis. These are both critical elements in effective advance care planning (ACP).

There is a lack of agreed markers to indicate when individuals with various life-limiting conditions enter the dying trajectory in their clinical course. Use of predictive tools should be considered for use in populations of patients (not individuals) to better understand which groups of patients might benefit from targeted, anticipatory discussions about end of life treatment preferences. Specialist groups with strong involvement in caring for patients with life-limiting illnesses, for example oncology, geriatrics, ICU, cardiology, neurology, respiratory, renal and general practice should consider the need for, feasibility and availability of such tools.

4.6 Inadequate end of life advance care planning processes

Recognising when patients have entered the dying phase, having iterative discussions about changing goals of care, preferably while the patient still has decision-making capacity, and identifying appropriate substitute decision-maker/s are mainstays of good EOL advance care planning. These also need to occur in community and primary care

settings and General Practitioners play an important role in this regard. While there is currently little local empirical evidence, it is anticipated that good EOL advance care planning will minimise future conflicts with families by aligning the patient, their family and the health team's expectations about the goals of care and preferred outcomes at the end of the patient's life.[24]

NSW Department of Health and Area Health Services are progressing advance care planning (ACP) implementation in NSW. Nonetheless, problems with substitute decision-making in EOL decisions are of ongoing concern, in particular difficulties in timely identification of the patient's preferred substitute decision-maker. Issues include:

- Where an individual is admitted to hospital or care facility with decision capacity, there are currently limited means of eliciting who they would want to make medical decisions on their behalf should they lose capacity. This differs to identifying the contact person on admission who is still confusingly called the 'Next-of-Kin'. This is a source of confusion in decision processes. In addition, a preferred substitute decision-maker other than prescribed by the NSW Guardianship Act 1987 requires appointment of that person as an enduring guardian and thus early identification will enable such appointments.
- There is widespread confusion and lack of understanding about guardianship & EOL decisions in general, including who decides and about what under NSW law. This is despite ongoing efforts by the Office of the Public Guardian and Guardianship Tribunal to educate health professionals in this area.
- There remains ambiguity in NSW Guardianship law as to the scope of powers of a 'Person Responsible' to consent to withdrawal and withholding of life-sustaining treatments.

Broad concerns were considered regarding the challenges in 'mainstreaming' Advance Care Planning (ACP) across clinical specialties. However, some specific concerns were identified in relation to decisions to withhold or withdraw dialysis. It appears that EOL advance care planning for these decisions is not common practice, at least not in all centres. These decisions sometimes result in disputes with families who seek continued dialysis beyond when the patient him or herself is able to determine its continued appropriateness, for example where the patient develops dementia.

22   Zhang B, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC, Block SD, Maciejewski PK, Prigerson HG. Health Care Costs in the Last Week of Life: Associations With End-of-Life Conversations. *Arch Intern Med* March 2009;169(5):480-488.

23   Keating NL, Landrum MB, Rogers SO, Baum SK, Beth A. Virnig BA, Huskamp HA, Earle CC, Kahn KL. *Physician Factors Associated With Discussions About End-of-Life Care.* Cancer 2010;00:1-10

24   Hillman K, Chen J. op cit. 2008

4.7 Impact of other system processes

4.7.1 Inflexible visitation policies

Restricted visiting hours are standard in some areas of some hospitals. This can relate to ensuring patients have sufficient rest time, or it can relate to a patient's unstable condition requiring interventions incompatible with prolonged presence of visitors at the bedside, for example in the ICU. Nonetheless, frustrations for family may accrue with limits imposed on being with their loved one and this may compound communication or other problems in some cases where EOL conflict occur.[25] Flexibility in visitation policy may need to be considered on a case by case basis so as to strike a balance of needs and priorities, especially in the context of an emerging conflict.

4.7.2 Inadequate rooms to hold family conferences

Many wards or units in hospitals reportedly have very limited or no readily available rooms for holding private meetings with families. Such rooms also provide a place to quietly and privately grieve. Privacy is an essential requirement for successful family meetings where EOL decisions are to be negotiated.

4.7.3 Gaps in documenting prior EOL discussions and decisions

It is widely recognised across most health systems that improved methods of documentation for capturing EOL discussions and decisions are needed to enable information to be handed over between care settings and acted on accordingly.[26] For patients with chronic conditions and repeated presentations to emergency departments, the burden may fall to families to restate previously agreed limits on treatment where documented decisions are unavailable. Repeatedly revisiting prior agreed decisions with different health professionals can trouble or upset families.

NSW Health will be implementing standardised state-wide resuscitation planning documentation. Additional detail may also be needed in the clinical notes in some cases about other agreed EOL decisions or the rationale for resuscitation limitation. Several models currently exist across NSW included that used at Sydney Children's Hospital (Appendix 4).

4.7.4 Distance & communication in rural areas

Ensuring timely EOL discussions with families where they live long distances from the hospital in rural and regional areas can be challenging. Some families have limited mobility related to factors such as child care, financial, or seasonal work commitments demands. This impacts on the ability to directly discuss the patient's condition. Where the patient's condition warrants urgent transfer to a metropolitan hospital, timely opportunities for proper EOL discussions can be limited and potential for communication breakdown increases. In such scenarios, the patient may be imminently dying before this is fully appreciated by their family and necessary discussions about treatment limitation may then appear premature or pressured to them.

4.8 Understanding cross-cultural issues

Heterogeneity of beliefs, values and customs between individuals from the same cultural background is widely recognised and means that presumptions about attitudes to EOL decisions must be avoided.[27] Careful exploration is needed with that individual or family about relevant beliefs and attitudes and their bearing on how EOL decisions should be approached. Cross-cultural misunderstandings and concerns may arise within generations of families, within or between treating teams, or between treating teams and families. A number of specific concerns were identified.

4.8.1 Managing large, extended families in EOL settings

Large, extended families are the norm in many cultures. Often members of the extended family participate in all aspects of family life, including decisions about medical treatment. This can differ significantly from nuclear families and how such decisions are typically made.

■ Managing visitation

Allowing sufficient visiting time for large numbers of extended family members to pay respects to a very sick or dying patient can be difficult to achieve in practice, notwithstanding that health professionals recognise that this may be culturally required as part of honouring their dying loved one. Tensions may be raised for family and health professionals where visitation is constrained by the

25 Davidson JE, Powers K. op cit. 2007
26 Prendergast TJ. Advance care planning: Pitfalls, progress, promise. *Crit Care Med* 2001;29:N34-N39.

27 Kagawa-Singer M. Blackhall LJ. Negotiating Cross-Cultural Issues at the End of Life: "You got to go where he lives". *JAMA* 19 Dec 2001;286 (23):2993-3001.

demands of care provision or inflexible visitation policy. Involving large extended families in conferences reinforces concerns raised earlier regarding limited access to appropriate waiting rooms. Inadequate accommodation for important family meetings can detract from smooth negotiations. Early engagement with the family, explaining the constraints of the health setting, can facilitate co-operation and understanding between the family and treating team.

- Determining appropriate decision-maker/s

Some CALD families, according to their culture, will vest authority for important decisions in other than the 'person responsible' as defined by the NSW Guardianship Act, for example adult children may be preferred over spouses. This can complicate decision-making processes.

'Close' family can include many more individuals than the nuclear family, for example in Aboriginal or Lebanese families, and excluding them from decisions can be highly inappropriate and generate conflict. Family conferences with 20 or more family members are common in some centres. While this should be respected, it creates significant challenges to achieving a consensus decision because agreements rely, in part, on continuity of participants with each family conference.

Chaplaincy services may provide support to assist some CALD families identify religious or other respected community leaders whose involvement in these scenarios may facilitate consensus.

4.8.2 Using interpreter services in EOL decisions

Interpreter services are a vital part of managing EOL decisions in cross-cultural settings. High demands on interpreter services in the NSW health system may mean that availability in individual cases can be limited to certain times. This is further complicated by the number of health professionals involved in an individual patient's care who may need their interpreting assistance.

In negotiating EOL decisions with families where interpreter assistance is needed, opportunities for the normal iterative follow-up on families' understanding about what was said during family conferences may be more limited. This probably means that negotiating treatment limitation decisions with CALD families with limited understanding of English will always take longer.

Interpreter continuity between and for each family conference was identified as desirable by clinicians, and is possible on request (to Area interpreter services) though probably difficult to achieve in practice.

Health professionals' understanding and use of interpreter services need to be improved. There is some limited training for health professionals as part of many hospitals' induction processes. New medical graduates, in particular, should receive information about how to optimally use interpreter services. Proactive advice from interpreters is appropriate when engaging with medical and other staff as to how best to use their expertise in EOL care settings. For example, it is probably not well appreciated by health professionals that interpreters should be briefed before a session, especially where difficult family dynamics are anticipated, or that interpreters can provide generic information about culturally specific issues but cannot provide an opinion about family dynamics & whether there may be emerging problems.

NSW Health policy *Interpreters – Standard Procedures for Working with Health Care Interpreters*[28] was noted. This policy outlines the requirements for interpreter impartiality and the need to declare personal relationships & withdraw from a case where necessary. However, in practice this can pose difficulties where a family is from a small cultural group and the availability of interpreters fluent in that language may be very limited. The policy also identifies the boundaries between interpreters offering culturally specific information and offering their personal views during client interview, in this case about EOL management. This can be a grey zone in some circumstances. Interpreters may need support & counselling themselves after EOL negotiations, especially if they have not worked in end of life settings before.

4.8.3 Orthodox groups and demands for aggressive treatment

Anecdotally, individuals and/or families from some orthodox Middle Eastern and Asian backgrounds may consider discussions about dying and related decisions to limit treatment as taboo, on cultural and (less often) religious grounds. In some cases, simply talking about end of life decisions is tantamount to 'giving up' and abrogating their responsibility, even filial duty to their loved one. Embarking on discussions about EOL treatment limitation has evoked hostile responses in some cases. No local evidence could be found however, to support the common perception that

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28 NSW Health, PD2006_053 *Interpreters – Standard Procedure for Working with Health Care Interpreters*, 2006

certain groups are associated with a stronger preference for aggressive treatments.[29]

EOL advance care planning has not been introduced widely across CALD groups in NSW at this time. It is difficult therefore to know yet whether anticipatory discussions about dying and related advance care planning will be appropriate, welcome, or if advance care planning discussions will have a favourable impact on preventing EOL conflict. Some cultural groups may instead prefer to rely on family to honour and protect their wishes at the time decisions are required, in particular where there may be a preference for aggressive treatment at the end of life.

4.8.4 Gender-based role differences

Care may be needed in conducting EOL discussions across gender lines in some CALD groups, as it may not be acceptable for women to participate directly in family conferences about EOL decisions. This can generate significant anxiety amongst health professionals who may not share these values and cultural norms. Such situations should always be handled sensitively and respectfully and consideration given to the cultural values, social networks and decision-making structures and processes held by the patient and their family. At the same time, however, such situations should be managed in ways that are in accordance with Australian legal standards for substitute decision-making.

4.8.5 Refugees and recent immigrants

Recent immigrants including refugees may have a limited understanding of our health system. This can be coupled with a mistrust of health professionals and the health system, perhaps based on previous experiences in their country of origin. Sadly, it is not unknown for some families to suspect that EOL decisions are being raised because they have not paid sufficient money to receive all appropriate medical care. Offers of money to treating doctors to secure longer treatment are not unknown. In such circumstances, it is possible that doctors' recommendations about EOL treatment limitation are perceived by those families to be tainted by the combined effect of their racial and financial status. Where families hold these suspicions, repeated explanation and reassurance may be required.

4.8.6 Misreading verbal communication

In some circumstances, health professionals may misread or misinterpret verbal responses from individuals from different cultural backgrounds, for example where there are volatile reactions.[30] Raised voices may not necessarily indicate hostility & conflict in some cultures. This may serve other purposes, for example emphasis, and may depend on a host of factors, including who the discussion is about, and between, and their authority and importance within the family and local community.

4.9 Risk management concerns and interface with legal processes

There appears to be widespread apprehension amongst health professionals about involvement in Court proceedings in relation to EOL disputes. There may be a misperception that these types of matters often end up in Court. In fact, there has been very little of any type of Court proceedings arising from the withholding or withdrawal of treatment in NSW, especially when one considers there are probably hundreds of such decisions made each day. There have been no claims for compensation in the past 10 years arising from this kind of scenario and there is approximately one case every 2 years seeking some type of order from a Court (excluding Guardianship Tribunal). Most cases do not progress to judgement and are resolved. In the unlikely event that these cases do result in proceedings, clinicians would be supported by their Area Health Service, Medical Defence Organisation or the Nurses Association. The NSW Health's Legal and Legislative Services Branch has accumulated a significant degree of experience in this jurisdiction and is a valued asset in advising on such matters.

Nonetheless, these cases may have contributed to a number of outcomes including reluctance on the part of some doctors to engage in EOL decisions, fear amongst nurses in some areas about engaging in EOL discussion with patient and families, and lowered morale in centres where clinicians have been required by their management to acquiesce to family demands for aggressive and, arguably, 'futile' treatment.

Role of DOH Legal and Legislative Services Branch

Timely access to expert legal advice may significantly reassure clinicians about how they should proceed. Some clinicians may also need reassurance that obtaining legal advice does not activate a process necessarily leading to Court. Access to expert legal advice, especially in this highly

29   Hillman K, Chen J. op cit. 2008

30   Hale SB. *Community Interpreting* 1st edition, Palgrave Macmillan, 2008, Australia

specialised area, is reportedly difficult in some Area Health Services. There also appears to be some lack of clarity at Area level as to the role of DOH Legal and Legislative Services Branch in providing advice in EOL conflict. Legal Branch continues to advise Areas regarding EOL decision-making concerns, especially where a dispute is emerging. However, such enquiries from Area Health Services need to be triaged via an appropriate senior contact at Area level to Legal Branch. Aside from Legal Branch's role in providing advice, and if necessary representing Public Health Organisations before Courts and Tribunals, it is only with awareness of current cases where EOL conflict is problematic that the Department is able to identify possible test cases to progress common law in the area of end of life decision-making.

Role of NSW Guardianship Tribunal

Prior to the establishment of the NSW Guardianship Tribunal (the Tribunal) and its more expeditious processes, decisions about guardianship, including end of life issues, were always made by the Supreme Court. Many health professionals however, do not have a good understanding as to the specific nature and extent of the Guardianship Tribunal's role in EOL conflict. The Guardianship Tribunal does not give legal advice, determine duty of care obligations, review advance care directives, or appoint the 'person responsible' amongst family members. However, the Tribunal can appoint guardians to make EOL decisions or can consent to specific medical treatment including palliative care. End of life decision making cases often involve disagreement between the person responsible, treating doctors and other family members, or situations where there is no consistency or consensus about a course of action for the patient. Medical practitioners may feel that it is in the patient's best interest to have a clear, single, legally appointed decision maker in relation to their medical care and they may wish to apply to the Tribunal for a guardian, for example the Public Guardian, to be appointed. The Tribunal may also provide consent to particular medical treatment being proposed by a practitioner where there is no person responsible or the person responsible has refused.

When the Tribunal appoints a guardian to make decisions about end of life issues, the guardian's role is to focus on making a decision which serves the best interests of the patient. It is not the guardian's role to ensure that consensus is reached within the patient's family about the decision which the guardian proposes to make, although the achievement of consensus is always a positive outcome.

A guardian is obliged to consult family members about their views but is not bound by these in making a decision. A guardian can make a decision about a patient even if their family members disagree with the decision or do not support it. The guardian's decision has legal authority despite the lack of consensus from family members.

Enduring and appointed guardians who have a 'health care' function under Part 2 of the NSW Guardianship Act can consent to treatment withdrawal.

Role of Office of the Public Guardian

The Office of the Public Guardian (OPG) can also make decisions about palliative care plans being formulated by doctors in adult settings, sometimes where there may be emerging or anticipated dispute with the patient's family. Variation in doctors' expectations when approaching the OPG about what this may comprise and who carries decision responsibility probably reflects a general lack of clarity about the roles of both OPG and the Tribunal in EOL conflict.

4.10 Health professionals' understanding of ethics and the law in relation to EOL decisions

The ethical and legal dimensions of end of life decisions are complex. The legal position in NSW is not settled and may change as case law in this area develops. Health professionals have varying levels of knowledge, skill and available supports to work through these issues as they arise in clinical practice. The following issues were identified as those where understanding could be improved.

- While withholding and withdrawing life sustaining medical interventions are considered legally and ethically equivalent and permissible, there persists a sense that stopping treatment is more problematic in this regard than starting it.
- Withholding or withdrawal of artificial hydration and nutrition is an aspect of care that reportedly raises concerns amongst both health professionals and the public. Nurses find this aspect of care anxiety provoking, at least in some settings. There is probably a misperception that provision of this particular medical intervention is mandatory, despite law to the contrary.[31] The ethical and legal justification for its cessation may

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31   Gardner; *Re BWV [2003]* VSC 173

be complex to work through in daily practice.

- The appropriate use of opiates in palliative care, when given in doses to relieve or avoid distress (e.g. during extubation when a decision has been made to withdraw ventilatory support from a dying patient), is possibly not well understood in practice, or at least raises fears/misconceptions about euthanasia and breaching the law.

- The term 'futile' treatment is used in clinical practice, despite its persisting ambiguity in medical ethics literature. There remains ongoing debate about what constitutes futile treatment, despite the law broadly supporting that health professionals are under no obligation to provide treatment deemed futile by medical consensus. A view amongst health professionals is possibly "if it's futile, can't we just say no?".[32,33] A more inclusive approach is needed to exploring divergent views between treating professionals and a family where arguably 'futile' treatment is at issue in an EOL conflict.

- Decisions about ceasing dialysis emerged as a difficult area of practice in some centres. It is unclear if this relates to advance care planning discussions not being routinely used to the degree that they might in renal services at this time. Alternately, there may be specific ethical and legal grey areas in withholding or withdrawal of renal support therapies at end of life that need clarifying for health professionals working in this clinical setting.

- There is a persistently inadequate understanding amongst health professionals about the role of 'Person Responsible' in so far as who decides, and what is permissible in EOL substitute decision-making in NSW. The current lack of clarity within the Guardianship Act in terms of scope of powers of person responsible in treatment limitation decisions further compounds this.

4.11 Expectations about modern medical miracles

Community expectations about what medicine can achieve and related end of life options can be unrealistic. This may be reflected in family responses in some cases. This is perhaps not surprising, given the media treatment of 'high-tech' interventions, cardiopulmonary resuscitation and their outcomes,[34,35] the latest scientific discovery, or the '1 in a million' case that seemingly miraculously recovers against the odds.[36,37] These broader representations may colour some families perceptions about what can be achieved in reversing pathology and forestalling death in some cases. In addition, information about disease and prognosis is often sought out via the internet by patients and families facing difficult treatment decisions. Only some of this information is authoritative.

Influencing societal perceptions about modern medicine and its limitations is a long term and very difficult prospect. However, potential opportunities may arise for a wide-ranging discourse with society about death and dying, given current national initiatives around EOL advance care planning. Professional societies, in particular intensive care or health consumer groups could lead such debate.

4.12 Specialisation in medicine and risk of fragmentation of care

One of the hallmarks of modern medicine is its increasing clinical and diagnostic specialist streams. While this has brought unequivocal benefits to patients in terms of enhanced clinical skills, knowledge and related practice improvements, management of the patient by multiple clinical teams comes with the inherent risk of fragmentation of treatment planning. Inadequate consensus on a collective management approach about end of life care can result. Different clinical teams provide information to families, often with inadequate communication between those teams. This is reportedly common in local practice. Management by multiple clinical teams may obfuscate where responsibility lies for timely introduction of anticipatory discussions about dying. However, clarifying this is essential to halt the 'investigation and intervention spiral' that too often accompanies the last 6 months of life.[38,39]

32   Rubin SB. If we think it's futile, can't we just say no? *HEC Forum* 2007;19(1):45-65.
33   Rubin SB. *When Doctors Say No: The Battleground of Medical Futility.* Indiana University Press 1998

34   Diem SJ, Lantos JD, Tulsky JA. Cardiopulmonary resuscitation on television: Miracles and misperceptions. *NEJM* June13 1996;334(24):1578-82.
35   Kirk Jones G et al. Public expectations of survival following cardio-pulmonary resuscitation. *Academic Emergency Medicine* January 2000;7(1):48-53.
36   Hitti M. *Firefighter's miracle recovery rare in long-term coma cases.* Fox News, Friday May 6 2005.
37   Natalie Morales, *'Dead' man recovering after ATV accident.* NBC News March 24, 2008
38   Kardamanidis K, Lim K, Da Cunha C, Taylor LK, Jorm LJ. Hospital costs of older people in New South Wales in the last year of life. *MJA* 1 Oct 2007;187(7):383-386.
39   Zhang B, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC, Block SD, Maciejewski PK, Prigerson HG. Health Care Costs in the Last Week of Life: Associations With End-of-Life Conversations. *Arch Intern Med* March 2009;169(5):480-488.

Not surprisingly, it is often difficult for clinicians to prognosticate beyond their own specialty. Emerging difficulties in negotiating EOL decisions can arise in settings unaccustomed to these decisions but where changing referral and treatment patterns mean increasing numbers of patients enter their dying phase in those locations, for example rehabilitation facilities. Emerging difficulties also arise when clinicians express prognoses or efficacy of treatments outside their area of expertise, as in some cases the information provided is in error.

A common cry amongst medical and nursing respondents was for earlier and more frequent referral to, and improved availability of palliative care services. Also identified was a stigma still associated with palliative care referral for a proportion of parents of seriously ill children & adult patients and their families. For some, this still implies the patient's impending or imminent death. Referrals may be vigorously resisted by families in some cases. Ongoing education with patients and families is needed about the proper scope of palliative care practice and that this is not limited to the terminal phase of care.

Overall, multidisciplinary expertise to enable good EOL care plan formulation was recognised as essential. Better coordination of such expertise in EOL care planning, including early family conferencing, is an important preventative component in EOL conflict. Improved availability of social workers in some settings to facilitate coordination of EOL discussions and care planning could assist in this regard.

4.13 Additional issues in paediatric settings

End of life decisions in children present heart-breaking choices, and have generated some complex and protracted disputes, including in NSW. Such EOL conflict may be fuelled by additional precipitating factors than in adult cases.[40] The following concerns were identified locally regarding EOL conflict in paediatric settings.

4.13.1 Transitioning to adult care settings

Transitioning children with chronic but ultimately fatal conditions to adult care settings may be a high risk time for conflicts about EOL decisions to emerge. Failure to plan ahead and across settings is a concern in transitioning these

children. At such times, family conferences, skilled communication and thorough ways of documenting treatment decisions so they are available across care settings become paramount.

There is a difference in understanding of the term 'end of life' in the paediatric setting where this may entail years until death, whereas this generally relates to the last 6 months of life in adults. This distinction is important for health professionals and families to appreciate, especially in regards appropriate care planning when a young person transitions to an adult care setting.

4.13.2 Presumptions about quality of life and use of resuscitation

Concerns were raised[41] that, in some cases, health professionals' quality of life judgements regarding patients with chronic, degenerative disease and disability were being made or used inappropriately, for example in a discriminatory way, to withhold life sustaining treatments. It is important that in all cases proper discussion with parents and care providers is sought. (See 4.4.4)

There appears to be persisting misperception in both paediatric and adult settings that the existence of a 'No CPR order' implies that other interventions are necessarily unwarranted, for example managing iatrogenic or readily reversible problems. Careful care planning around use of life sustaining treatment is needed for long term, ultimately fatal conditions, especially as death is approaching. This must include accessible documentation of contingencies for precipitous deterioration to avoid disputes about appropriate management, especially in Emergency Departments as the interface between home, residential and acute care settings. Parents often want and can benefit from receiving a copy of the resuscitation plan to assist in conveying decision outcomes at the time of clinical need, especially where the child presents to a number of care settings.

Several Area Health Services are currently using documentation around End of Life Care Planning. One example from Sydney Children's Hospital is attached as Appendix 4.

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40   Wright B, Aldridge J, Wurr K, Sloper T, Tomlinson H, Miller M. Clinical dilemmas in children with life-limiting illnesses: decision making and the law. *Palliative Medicine* 2009; 23: 238–247.

41   NSW Ombudsman, *Report of Reviewable Deaths in 2005 Volume 1: Deaths of people with disabilities*, November 2006

4.13.3 Parents as substitute decision-makers

In most cases, two parents share equal decision-making responsibility for their sick child and both need to be in agreement about proposed limitation of life-sustaining treatment. Parental consensus however, may not always exist, at least for a time. Information about prognosis and EOL treatment options where parents are in conflict needs to be delivered with care as information can be interpreted differently and inadvertently fuel divisions. Divisions between parents impact not only their effectiveness as decision-makers, but can also seriously and sometimes permanently impact on their relationship with attendant implications for family dynamics and support.

As in adult settings, parents who demand 'futile' treatment may be characterised as not 'accepting' death and 'being in denial'.[42,43] Expressly recognising and validating parents' intensely-felt love for their dying child is supported, even while continuing dialogue about appropriate treatment withdrawal. This may engender an enhanced sense of control for those parents experiencing anguish and anticipatory loss in these scenarios.[44]

Paediatric clinicians, of course, are not exempt from potential feelings of discomfort in recognising and allowing death in children. However, this will complicate EOL negotiations, hamper honest communication and block opportunities for ongoing feedback with parents. Negotiating use of aggressive treatment as the chance of success continues to diminish is always difficult. It is a particularly fine line for paediatric clinicians to tread on a case-by-case basis between addressing parents' persisting hopes, avoiding excessively paternalistic engagement in decision-making, and ameliorating potential feelings of guilt in parents where they may feel that agreeing to treatment

limitation is akin to 'giving up', abandoning their parental responsibility to protect their offspring, or worse being responsible for their child's death. The intensity of these emotions can generate extreme aggression and occasionally irrational behaviour. Similarly, health professionals, especially those who are parents themselves, may align themselves with parents under such pressure, clouding their own judgment about what might be in the child's best interest. This may generate significant team disharmony. Clinical leadership and insight into team dynamics in such circumstances are required. Clarification of role delineation and setting reasonable limits around acceptable behaviours may assist in re-establishing better communication.

The transitioning of adolescent patients to adult services, sometimes at a critical phase in their disease deterioration, can be a time of significant emotional challenge for patients, families and staff. The use of strategies such as clear documentation around existing end of life care discussions (e.g. Appendix 4) can reduce the risk of conflict for the new team taking over care.

42 Gillis J. "We want everything done." *Arch Dis Child* March 2008;93(3):192-193.

43 Lantos J. When parents request seemingly futile treatment for their children, *The Mount Sinai Journal of Medicine* May 2006;73 (3):587-589.

44 Gillis J, Rennick J. Affirming parental love in the pediatric intensive care unit. *Pediatric Critical Care Medicine* 2006;7(2):165-8.

Responses and recommendations

For implementation of the following approaches to be effective, this first requires a broader acceptance that EOL decisions are an essential aspect of care, that discussions with patients and families about EOL decisions are better introduced earlier than later in the patient's 'dying' trajectory, and that a greater number of medical specialties should embrace these discussions.

The following recommendations are made for the NSW public health care system.

5.1 Allowing time and repeat discussions

Recommendation

5.1.1 Allowing time and holding iterative, sensitive and open discussions with families is sufficient to resolve the vast majority of disputes. Time and repeat discussion therefore continue to be the mainstay of prevention and management of EOL conflict.

5.2 Holding family conferences for EOL decisions – best practice

Of the interventions identified in the project's literature review, the importance of regular, properly managed family conferences or meetings as a means of preventing and managing EOL conflict has the strongest evidence base. Holding regular meetings with family and other substitute decision-makers is routine practice in ICUs in NSW. However, this is not routine practice, for a number of reasons, across other specialties and care settings. These are arguably easier to manage in the relatively controlled environment that ICU provides compared to other clinical settings.

Broader adoption of EOL family conferences is supported, especially in clinical settings beyond the ICU, recognising that there are additional practical barriers posed by these environments. These meetings can falter in a number of ways. Promulgating information across NSW hospitals about 'how to do them well' is therefore recommended.

A number of specific issues were identified in the literature[1,2,3,4] and through consultation regarding determinants of success in holding EOL family meetings:

- Proper preparation for such conferences must include reaching a consensus about the medical position and best way forward.
- Getting the 'right' people from both the family & health team at meetings is important. This may mean more than one senior doctor where multiple medical teams are involved.
- Establishing a family's understanding about the patient's situation, their concerns and patient's values should be attended before giving the family new information.
- Continuity in which clinician who leads and which health professionals (for example senior nurse, social worker or chaplain) participate in family conferences is important, albeit difficult with rotating clinical shifts. Trying to get consistent participants in both family and treating team/s members is equally important.
- The person leading the family conference must be open & able to engage, knowledgeable about prognosis and prepared to express that, and be briefed beforehand about the patient's condition, social & other circumstances.
- There can be a fine line between repeated information about poor prognosis and possible treatment limitation being useful to a family, and repetition that is perceived as coercive.
- Where an EOL conflict continues over time without resolution, it may be appropriate to nominate a single professional as point of contact.
- Family conferences with CALD families often bring additional complexities, such as language barriers, differing cultural expectations and preferred communication approaches.

1   Curtis JR, White DB. Practical Guidance for Evidence-Based ICU Family Conferences. *Chest* 2008;134(4):835-843.
2   Lautrette A. et al. End-of-life family conferences: Rooted in the evidence. *Crit Care Med* 2006;34 (11):S 364-372.
3   Truog RD. et al. Towards interventions to improve end-of-life care in the pediatric intensive care unit. *Crit Care Med* 2006;34 (11):S373-379.
4   Hillman K, Chen J. op cit. 2008

- Health professionals should not outnumber the family members present at family conferences. This can be difficult, given legitimate medical, social work and nursing participation but can unwittingly send the wrong message to a family.

- It can be difficult but ultimately productive for health professionals to be able to listen to anger expressed by participants during family conferences, albeit threats are never acceptable.

- There is some evidence[5] that achieving a consensus on an EOL decision first needs agreement between treating doctors and the family on the patient's terminal status and that this, in turn, critically relies on an accumulation of evidence about the patient's poor prognosis. Expressing uncertainty about the patient's likely poor outcome (and some uncertainty is common in ICU settings) may therefore decrease the chance of coming to a consensus.

- Frequent meetings may be perceived by some families as forcing their hand. For example, daily meetings, though routine in most Intensive Care Units where a patient is deteriorating, may not necessarily be welcomed by some families. This should be explored on a case by case basis.

- Where adult patients have decision-making capacity their permission should always be sought before information about their condition is shared with family members or with others and before a family conference is arranged. Should they agree to a family conference competent patients should always be offered the opportunity to attend and to participate in discussions.

Recommendation

5.2.1 **Develop and promulgate best practice advice for the NSW health system on how to plan for and run effective EOL family conferences.**

5.2.2 **Incorporate this advice into existing and future Area Health Service EOL care pathways or other care plans.**

5.2.3 **Consider the role of senior, appropriately skilled social workers or nurses in identifying the need for EOL family conferencing.**

5.2.4 **Improve access to social work services in areas of need to facilitate multi-disciplinary EOL care planning through i) EOL family conference coordination and ii) follow-up with families.**

5.2.5 **Public health organisations should consider the adequacy of access to suitable meeting areas to hold family conferences, especially in those institutions where extended families are common.**

5.3 Seeking second medical opinion to assist family decision-making

In clinical practice generally, the triggers for sourcing a second medical opinion are either a degree of clinical uncertainty, or concerns on a patient or family's part that they are receiving accurate and/or complete information to assist in decision-making. The first scenario is well embedded in routine clinical practice where clinicians frequently refer cases to respected colleagues within and beyond their own specialty for advice. This was not the focus of the Working Group's deliberations. Instead, they focussed on the latter, in particular where a conflict is emerging and a second medical opinion might be a potential 'circuit breaker' to aid dispute resolution.[6,7,8] Obtaining second opinion in this context is widely supported as part of the clinical landscape but the 'how to' remains unclear for many clinicians.

Whilst seeking a second opinion earlier may help (re) establish trust, this might be seen by some families as collusion between doctors and a coercive influence. Undoubtedly, this would vary on a case by case basis but will be more likely helpful and accepted if every effort is taken to be open and independent. At the least, potential use of a second opinion should not be set up as adversarial, whether proactively offered by the treating team where conflict is developing, and even more so when requested by a family. A number of issues in regards to sourcing second opinion in this context were identified:

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5 Aldridge M, Barton E. op cit. 2007

6 Axon A. et al Ethical and legal implications in seeking and providing a second medical opinion. *Digestive Diseases: Clinical Reviews* 2008;26:11-17..

7 Ho A. "They just don't get it!" When family disagrees with expert opinion. *Journal Medical Ethics* 2009;35:497-501.

8 Worthley L. Could we have a second opinion? *Crit Care and Resus* 2000;2:89-90.

- Such processes must ensure sufficient independence from the treating team to ensure that a family would view this as properly impartial advice.
- Doctors providing a second opinion have obligations to two groups: the patient/family *and* the treating team. This has a bearing on the need for negotiating appropriate communication channels between the family, treating team and second opinion provider on a case-by-case basis.
- The second opinion provider should be provided with access to all relevant medical notes and test results and direct examination of the patient should be encouraged.
- A request from a family for a second opinion by a complementary medicine practitioner should be considered an *alternate* opinion, not a second medical opinion. Such a request will require different considerations.
- Where a doctor has been specifically requested by the family and there are questions as to their expertise, the institution should retain the right to refuse to engage that second opinion.
- Sometimes the patient's or family's general practitioner can be helpful in identifying a suitably qualified medical officer whose opinion would be accepted by the family, even if that is from a list of individuals previously sourced by the health service.
- A patient's general practitioner may also be well placed to convey views previously expressed by the patient about their values as applicable to the current situation and their care.
- The process for sourcing a second opinion should consider necessary resource constraints, for example exclude exorbitant travel costs, and the limitations on availability of respected colleagues to travel very long distances sometimes at short notice, for example interstate or overseas.
- The person giving that opinion should have current medical indemnity insurance.

Recommendation

5.3.1 **Develop standards and an agreed process for sourcing second medical opinion as an adjunct to resolving EOL conflict, in conjunction with relevant professional and other bodies.**

5.4 Improving capacity in cross cultural settings

Misunderstandings arise in EOL decision-making in cross-cultural settings. The precipitants and impact of these, specifically as they occur in NSW, are not thoroughly understood or empirically investigated at this time.

Recommendation

5.4.1 **Improve interface with the interpreter services as they are involved in negotiations about EOL decisions through:**

1. Standardisation of training for interpreters, including clinical rotations to EOL settings;

2. Better understanding and use of interpreter services by health professionals through i) training programs and ii) interpreters advising health professionals as to how to optimally work with them in EOL settings; and

3. Improved availability of interpreters, specifically that priority access be given for cases involving EOL conflict.

5.4.2 **Consider the availability and applicability of targeted cultural competency training for health professionals working in settings with significant CALD populations and where EOL decisions are common.**

5.5 Improving advance care planning

A strengthened systematised approach to advance care planning (ACP) in NSW is supported. This broadly involves:

- Better identification of when patients enter the last 6-12 months of their life and having anticipatory discussions around dying;
- Better identification of the substitute decision-maker, such as eliciting who the patient him or herself would want as their substitute decision-maker. (If this differs to the Guardianship Act's hierarchy of 'person responsible', then this requires that person to be appointed as an enduring guardian.);
- Making advance care planning discussions routine in relevant practice settings; and
- Clear processes for making advance decisions and appropriate documentation to transfer decisions between care settings.

Recommendation

5.5.1 **Promote identification of the appropriate substitute decision-maker by:**

- Developing and promulgating a tool to improve identification of the patient's substitute decision-maker. The tool being developed by HNEAHS for this task should be reviewed for its applicability across Area Health Services; and
- Minimising barriers to the appointment of enduring guardians.

5.5.2 **Distinguish the term 'Next-of-Kin' and its use from the term to denote the substitute decision-maker who makes treatment decisions on the patient's behalf i.e. 'person responsible'.**

5.5.3 **Refer potential use of tools to better delineate patient demographics which predict where death is likely in next 6-12 months to the relevant specialist Colleges nationally for their consideration. This aims to target anticipatory discussions about dying with patients and their families.**

5.5.4 **Clarify the role and legal authority of the person responsible when a decision to focus on palliative care is needed on behalf of a patient lacking capacity.**

5.5.5 **Assess the adequacy of EOL care in the transitional setting, in particular for paediatric patients transitioning to adult settings.**

5.6 Improving communication skills

Managing EOL family conferences well is a skill and, as such, requires training and supervision and mentoring in those undertaking this important aspect of clinical care. Improving communication skills through education strategies targeting EOL decisions is critical to improving prevention and management of EOL conflict.

Recommendation

5.6.1 **Refer development of clinically relevant communication skills training programs targeting key medical specialties with greatest interface with EOL decision-making to the specialist Colleges for consideration. This should include palliative care, ICU, oncology, neurology, cardiology, renal and geriatrics as priority specialties. Such program should be incorporated into continuing education in the postgraduate and professional setting.**

5.6.2 **Prioritise development of sound communication skills in doctors, nurses and allied health professionals as they relate to 'difficult discussions' at both under- and post-graduate levels and related opportunities for supervision in practice.**

5.7 Improving understanding of ethical & legal issues in relation to EOL decisions

Recommendation

5.7.1 **Consider existing gaps in written information that is available for families on issues relevant to EOL decisions, such as use of cardiopulmonary resuscitation, artificial hydration and nutrition, or 'how to' when considering EOL advance care planning, including related concerns such as bereavement counselling, 'anticipatory grieving', or available home care support.**

5.7.2 **Consider referring appropriate ethical issues, such as withholding/ withdrawal of artificial hydration and nutrition to the Australian Health Ethics Committee for national resource development.**

5.7.3 Refer inclusion of EOL conflict and related ethical, legal, clinical and social issues into medical grand rounds programs and other institutionally based education sessions to Area Medical Staff Councils for their consideration.

5.7.4 Improve health professionals' understanding of the role of the Guardianship Tribunal in EOL decisions through appropriate mechanisms, in consultation with the Guardianship Tribunal, Office of the Public Guardian and NSW Health's Legal & Legislative Services Branch.

5.8 Escalating management of end of life conflict: Options

In a proportion of cases, preventative measures such as proper advance care planning and good negotiation at the bedside will be insufficient to resolve an EOL conflict and additional measures will be required.

'High level' EOL conflict pose particular difficulties for all involved and may entail intractable disputes, where the family chooses to take the details of the case to the media, where litigation is underway, and/or where threats to health service personnel have been made.

When management of an EOL conflict is escalated beyond the treating clinicians, this is likely to involve participation of, and oversight by those with responsibility for organisational & system risk management, such as senior Area administration and the Department of Health, including Legal Branch and/or Media Unit. Even where management of an EOL conflict is escalated to these levels, this does not diminish the need to support treating clinicians who are continuing to provide care and who must engage in ongoing discussions with that family. As one clinician commented, "It's a lonely business."

An appropriate point for escalating conflict management might be where obtaining a second medical opinion has been refused or fails (Figure 1). The following sections discuss a number of options which could be available to health professionals when moving a conflict from the bedside through other institutional processes, possibly to the Courts or the Guardianship Tribunal.

5.8.1 Obtaining legal advice and/or legal intervention

Recommendation

5.8.1.1 Advise Area Health Service clinicians and administrators that legal advice may be sought from DOH Legal Branch in cases involving escalating EOL conflict. Such requests must be triaged through a nominated senior Area administrator.

5.8.2 Mediation or 'facilitated negotiation' in end of life conflicts

The use of mediation in resolving EOL conflict was identified
as an area warranting further examination in the literature review undertaken to inform this project.[9] Current NSW Health policy[10] already recommends repeat discussions and the use of support persons for 'facilitation', meaning the use of a third party to help resolve conflicts. That third party is to be independent of the treating team. This concept of 'facilitation' shares features with most models of mediation.[11,12]

However, in considering use of 'mediation'– a practice weighted to legal contexts – some limitations were identified. Mediation, as it is used to resolve legal disputes, is a form of dispute resolution in which the parties are assisted by an independent mediator whose role is to assist in settling a dispute and reaching a decision. The mediator does not have the authority to decide the outcome. The aim is to bargain towards a compromise position, usually a sum of compensation acceptable to the parties. This model poses particular problems when applied to end of life decisions. The Area Health Service is legally responsible for treating the patient in accordance with its duty of care. This therefore limits the AHS capacity to compromise in mediation. For example, the AHS could not agree to resolve a dispute by continuing treatment that was viewed by the treating clinicians as futile and not in the patient's best interests. In addition, it is not necessarily clear who represents or speaks for the patient if they are incompetent.

Facilitated communication and counselling by an

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9   Hillman K, Chen J. op cit. 2008.
10 NSW Health, GL2005_057 *Guidelines for end-of-life care and decision-making*, March 2005.
11 Boulle L. *Mediation: Principles, Process, Practice.* 2nd Edition, Butterworths Australia, 2005.
12 Astor H, Chinkin C. *Dispute Resolution in Australia.* 2nd Edition, Butterworths Australia, 2002.

independent facilitator, for example a skilled social worker or psychologist may however assist in resolving communication issues in end of life conflicts. This may allow the parties to express their views, feel heard and have issues clarified in a supported environment. It is unlikely that legal mediation, at least in the model used for resolving court proceedings, is appropriate.

Although commentary[13][14] was available, there was little evidence available regarding applicability of various mediation models and their efficacy, specifically in resolving conflict in EOL decisions.

There are a number of potentially applicable models of 'facilitated negotiation', for example so-called 'bioethics mediation' as championed by Dubler and Liebman[15] in the US and practised in some centres in that country. This warrants further investigation but was beyond the resources of the Working Group.

Recommendation

5.8.2.1 **Refer expanded use of 'facilitated negotiation' in end of life conflicts to the Health Care Complaints Commission for advice, given their current role in mediating complaints handling. Appropriate model/s and their possible limitations should be explored and a suitable model evaluated in practice.**

5.8.3 Role of Clinical Ethics Committees and clinical ethics consultation

Use of Clinical Ethics Committees (CEC) and ethics case consultation were identified as a potential strategy for resolving EOL conflict in the project's literature review[16] and in a recent Australian Supreme Court ruling.[17] However, there is limited evidence and lack of consensus internationally and in Australia as to the role, models and efficacy of Clinical Ethics Committees, in particular in regards managing EOL conflicts.[18],[19]

There is a distinction between ethics case consultation (where an appropriately skilled individual consults the family and clinicians to explore the issues 'at the bedside') versus referral of a disputed case to an institution's Clinical Ethics Committee for discussion, advice or, in some other jurisdictions, adjudication. Given the paucity of evidence about the effectiveness of CEC directly resolving these kinds of disputes 'by committee' and the legal and other problems with them 'adjudicating' on a case, the Working Group did not support this role for Clinical Ethics Committees. There is also some limited evidence for lack of clinician support in NSW for their role in mediating EOL conflict.[20]

However, existing CEC in NSW can, and sometimes do provide advice on the ethical dimensions of an EOL conflict to clinicians on request to assist them in their own decisions and efforts to resolve these disputes. The current role of CEC in ethics case consultation is outlined in NSW Health Policy Directive Clinical Ethics Processes in NSW Health.[21] Formal clinical ethics case consultation is currently available in three NSW Area Health Services (HNEAHS, SSWAHS and SESIAHS) & at St. Vincent's Hospital via the Plunkett Centre. Local empirical data about ethics case consultation is needed.

Where Clinical Ethics Committees exist, they can play an important role in promoting and overseeing clinical ethics processes within an institution. These potentially include overseeing ethics case consultation at the bedside undertaken by an appropriately skilled and knowledgeable professional, use of ethics grand rounds in educating health professionals, developing or advising on local policy, or generating other means of supporting health professionals in addressing ethical concerns in their practice.

The Working Group noted a current 2 year research project being undertaken by University of Sydney in conjunction with NSW Health ('*Developing Clinical Ethics Capacity in NSW Through Partnership*' project) to develop an evidence base and related recommendations for establishing appropriate clinical ethics support processes across the NSW health system.

13   Bowen T. Using mediation in situations of withholding or withdrawing life-sustaining treatment: a New South Wales perspective. *Journal of Law and Medicine* 2009;17:74-81.
14   Harvard Law School, Negotiating Death: ADR and End–of-Life Decision Making. *Harvard Negotiation Law Review* 2004;9:253-330.
15   Dubler N, Liebman C. *Bioethics mediation: A Guide to Shaping Shared Solutions. United Hospital Fund of New Yor*k, USA, 2004
16   Hillman K, Chen J. op cit. 2008.
17   *Inquest into the death of Paulo Melo* [2008] NTMC 080
18   Schneiderman LJ. Effect of ethics consultations in the intensive care unit. *Crit Care Med* 2006;34(11):S359-S363.
19   Faunce T.A. Stewart C. *The Messiha and Schiavo cases: third party ethical and legal interventions in futile care disputes.* MJA 5 Sept 2005;183(5):261-263.

20   Zib M, Saul P. A pilot audit of the process of end-of-life decision-making in the intensive care unit. *Critical Care and Resuscitation* June 2007;9(2):213-218.
21   NSW Health, PD 2006_027, *Clinical Ethics Processes in NSW Health,* 2006

Recommendation

5.8.3.1 Area Health Services should establish transparent processes for managing EOL conflict and other ethical dilemmas in clinical practice. These should incorporate any local requirements, relevant policies for escalating disputes in the clinical setting to senior administration, and how to access clinical ethics resources and processes (where these exist).

5.8.3.2 Evaluate ethics case consultation in a centre currently providing such a service (for example by audit of patients/families/ health professionals).

5.8.4 Providing support to clinicians involved in escalating/protracted EOL conflict

The Working Group considered the need for better support mechanisms for health professionals engaged in EOL conflict. These disputes can lead to health professionals feeling isolated and demoralised.

Establishment of a state-wide consultation service to provide support to clinicians grappling with an intractable or escalating EOL conflict was considered. This potentially involved a small team of clinicians with previous experience in managing these disputes to provide:

- Real-time advice regarding possible strategies that the referring clinician or administrator may not have considered or used;
- Process clarification for doctors, for example in sourcing second medical opinions for families in a disputed case;
- Personal support to clinicians; and
- Post-hoc review of cases involving significant EOL conflict.

There were significant obstacles with this potential response to EOL conflict. The appropriate role/s of this advisory group was difficult to delineate, considering overlapping responsibilities of Area administration, clinical review committees and others. Staffing such a service 7 days a week with willing and highly expert individuals was considered to be largely prohibitive. In addition, this model could raise issues already being examined by other professional bodies, for example

the professional Colleges in regards standards for credentialing specialists to be expert witnesses in the Courts. However, an informal mentoring process within specialty groups across hospitals that operated on a 9am to 5pm basis could be useful.

Recommendation

5.8.4.1 A state-wide advisory service was considered but lack of clarity as to its role and how it would be fulfilled meant that it is not recommended at this time.

5.8.4.2 Area Health Services develop policy for supporting staff involved with difficult EOL conflict situations to include individual debriefing, caseload and counselling support, and/or broadly inclusive and confidential case conferencing for all affected staff conducted by Head of Department and/or social work team and/or palliative care team.

5.9 Develop an EOL conflict 'tool kit' for managing escalating EOL conflict

The utility of a collated resource of information about managing an EOL conflict where time and iterative discussions do not generate a consensus was considered. This should be developed with a target audience and/or dissemination point being Director, Clinical Operations or similar level. This toolkit might include information on:

- How to seek second medical opinion for EOL dispute resolution;
- Local process for engaging Executive support when escalating management of EOL conflicts;
- How to seek legal advice in EOL conflict;
- The role of the Guardianship Tribunal in EOL conflict; and
- A check list/s in preparation for approaching the Courts, the Guardianship Tribunal, or Office of the Public Guardian for decisions in EOL situations.

Recommendation

5.9.1 **NSW Health develops a 'toolkit' for managing escalating end of life conflicts.**

5.10 Evaluation and learning from practice

The current absence of available data about EOL conflict is a significant obstacle to improved practice in this area. Evaluation of these disputes in and across institutions could provide useful insight into what works, rather than individuals or small teams reflecting on anecdotal experience. Auditing of deaths to include assessment of the quality of dying would make a useful contribution to evaluating end of life care, including where EOL conflict occur. Definition of 'reportable conflict' will require careful consideration. The lack of local empirical evidence to guide best practice development should be addressed.

Recommendation:

5.10.1 **Introduce audit/evaluation of EOL conflicts within NSW Intensive Care Units and other clinical areas where EOL decisions are frequent to enable evaluation of EOL conflict locally as part of existing quality review processes.**

5.10.2 **Establish routine data collection on EOL conflicts in appropriate agencies, for example Health Care Complaints Commission, Clinical Excellence Commission, and others as appropriate.**

5.10.3 **Death auditing specifically should be established by an appropriate NSW agency to evaluate quality of dying and related EOL conflict.**

5.10.4 **Recognise, support and refer the following priorities for an Australian EOL decision-making research agenda:**

- Establishing local best practice in managing family conferences in EOL settings;
- Effectiveness of second medical opinion as an adjunct in resolving EOL conflict;
- Auditing the NSW experience in cross-cultural misunderstandings in EOL settings;
- Effectiveness of current legal mechanisms for resolving EOL conflict; and
- Use and effectiveness of ethics case consultation in NSW public health institutions where this is current practice.

SECTION 6

Conclusion

The majority of end of life decisions are well managed in the NSW health system. Allowing time and holding iterative, sensitive and open discussions brings a resolution in most cases of conflict. However, there are no quick fixes and a number of elements and processes need to come together to optimally resolve these disputes while effectively supporting those involved.

The Working Group has resisted recommending development of another set of 'guidelines' for resolving end of life conflicts, and certainly development of 'futile treatment' guidelines. The Working Group has instead endeavoured to identify a range of practical supports that may better prevent or manage these conflicts.

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These recommendations seek to address the system enhancements needed to improve practice in this difficult area of end of life decision-making. Some of these recommendations will be potentially actionable in the short term and will have a reasonable impact, for example data collection and education around managing EOL family conferences. Others are no less important but are long-term prospects, for example improving communication skills, improving multi-disciplinary care coordination, or reconciling community perceptions about medical miracles with the reality of current technology. The scope and number of recommendations provided in this Report reflects the complexity of these disputes where clinical, cultural, social, ethical and legal concerns often converge.

Factors contributing to EOL conflicts

Failure to evaluate EOL practice so as to know 'what works' in preventing EOL disputes

Lack of clinical consensus where multiple clinical teams transmit mixed messages to families

Pre-existing intra-familial factors & dynamics Psychopathology, maladaptive responses

Perceived or real **time pressures** on family to decide

Patient's wishes unknown re use of life sustaining treatments

Failure to identify the appropriate substitute decision-maker

Society's expectations re what medicine can deliver in an Australian setting (influence of media, role of internet)

Gaps in understanding about **EOL ethics & law**

Lack of effective local **negotiation mechanisms** in clinical settings

EOL Conflict Contributing factors

Institutional risk management approach including clinicians' apprehension about engaging in legal processes

Ethnicity & religion
- Different decisional/ communication styles
- Language barriers
- Sense of feeling 'marginalised'
- Conflicting religious values or beliefs
- Cultural competency concerns
- Assumption of cultural homogeneity

Emotional responses to loss: shock, distress, fear, denial, anger

Specialist disciplines devolving EOL decisions to other specialties e.g. to palliative care & ICU

Uncertainty re appropriate locus of decision responsibility
Clinicians being afraid to provide clear recommendations to patient/family re EOL decisions &/ or family believing they have to take prime responsibility for medical decisions at EOL

Communication problems
- Skills
- Missed opportunity for early discussions
- Avoidance of 'difficult' discussions
- Limited time

Failure by clinicians to **recognise dying and convey poor prognosis**
Related misunderstanding by family re what constitutes clinical improvement or deterioration

Process of end-of-life decision-making

Source: NSW Health, GL2005_057, Guidelines for end-of-life care and decision-making, March 2005

APPENDIX 3

Working group membership

1. Dr Peter Saul (Chair), Senior Intensivist, John Hunter Hospital, HNEAHS & Director, Clinical Unit in Ethics & Health Law, University of Newcastle (expertise in EOL ethics and practice)

2. Margaret Bramwell, Deputy Director Social Work Department, Royal North Shore Hospital, NSCCAHS (expertise in clinical care – counselling & social work)

3. Dr Michael Brydon, Director of Clinical Services, Sydney Children's Hospital, SESIAHS (expertise in senior medical administration)

4. Esther Cho, Legal Officer, Guardianship Tribunal (expertise in guardianship and health law)

5. Associate Professor Josephine Clayton, Associate Professor of Palliative Care, Sydney Medical School, Faculty of Medicine, University of Sydney & Palliative Care Specialist Physician and Head of Department of Palliative Care, Royal North Shore Hospital, NSCCAHS (expertise in communication in medical and health settings & expertise in clinical care – palliative care)

6. Dr Jonathan Gillis, Senior Staff Specialist in Intensive Care and Palliative Care Physician, The Children's Hospital at Westmead & Clinical Associate Professor, The University of Sydney (expertise in clinical care – paediatrics)

7. Dr Theresa Jacques, Director Department of Intensive Care, The St George Hospital, SESIAHS & Conjoint Associate Professor, University of NSW (expertise in clinical care – adult ICU)

8. Associate Professor Ian Kerridge, Director Centre for Values Ethics & the Law in Medicine, University Sydney & Staff Specialist Haematologist/Bone Marrow Transplant Physician, Westmead Hospital, SWAHS (expertise in clinical ethics)

9. Julie Letts (Secretariat), Principal Policy Analyst (Clinical Ethics), Research, Ethics & Public Health Training Branch, NSW Health (expertise in policy development & clinical ethics)

10. Blaise Lyons, Principal Legal Officer, Legal and Legislative Services Branch, NSW Health (expertise in health law)

Sample End of Life Care Plan
(Sydney Children's Hospital)

Sydney Children's Hospital
A Facility of South Eastern Sydney Area Health Service

END OF LIFE CARE PLAN

Surname		Medical Record Number
Other Names		Date of Birth
Classification	Sex	Admission Date
Senior Medical Officer		Hospital/Ward

(affix label)

FOR: _____

Parental Contact(s)

Name: _____ Relationship: _____ Contact No: _____

Name: _____ Relationship: _____ Contact No: _____

Date of Initial Plan: _____

(NB: There must be a dated entry for this date in the hospital continuation notes recording the meeting held to formulate the ELCP and those present.)

(1) **Diagnosis:** _____

(2) **Problems:** _____   _____

_____   _____

_____   _____

(3) **Goals of Treatment:**

Organ donation has been discussed and the child is ☐ or is not ☐ a suitable donor. *(Tick one box)*.

END OF LIFE CARE PLAN

ELCP for Name: _____ DOB: _____ MRN: _____

(4) General Support Measures

4.1

			Yes	No	Comments
Nasopharyngeal suctioning			☐	☐	_____
Fluids / Nutrition	-	IV	☐	☐	_____
	-	NG	☐	☐	_____
	-	oral	☐	☐	_____
	-	IG	☐	☐	_____
Blood Products			☐	☐	_____
Antibiotics			☐	☐	_____

4.2 Measures to be taken for the relief of pain and discomfort:

4.3 Additional Instructions and/or investigations

4.4 Ambulance bypass endorsed   Yes ☐   No ☐

(*NB: This requests the ambulance to bring the child to Sydney Children's Hospital rather than the closest hospital in an emergency*).

2.

ELCP for Name: _____ DOB: _____ MRN: _____

(5) Management of Acute Deterioration

5.1 Who to call

		Yes	No	Comments
Call:	Arrest Team	☐	☐	_____
	Others	☐	☐	_____

5.2 Acute measures

	Yes	No	Comments
Nasopharyngeal suctioning	☐	☐	
Supplemental oxygen			
- passive	☐	☐	_____
- active (bag & mask)	☐	☐	_____
Intubation	☐	☐	_____
Cardiac Compression	☐	☐	_____
Electrical Cardioversion	☐	☐	_____
Arrest medications - (adrenaline, atropine, $NaHCO_3$, calcium, fluid bolus)	☐	☐	_____

3.

ELCP for Name: _____ DOB: _____ MRN: _____

(6) Clinical Contacts

6.1

Name: _____   _____

Position: _____   _____

Contact No: _____   _____

6.2 Emergency Contact:

NB: *To be contacted if the abovementioned primary contacts are unavailable.*

Name: _____

Position: _____

Contact: _____

(7) Managing Doctor's Signature
(Initial and subsequent)

Date	Print Name	Signature
Date	Print Name	Signature
Date	Print Name	Signature
Date	Print Name	Signature
Date	Print Name	Signature
Date	Print Name	Signature
Date	Print Name	Signature

) Discontinuation: Specify date and time this order is rescinded:

Date	Print Name	Signature

Sydney Children's Hospital	Clinical Standards and Practice Manual	ELCP Working Party
Section: 2		Effective date: 1 May 2004

GUIDELINES FOR FORMULATION OF AN END OF LIFE CARE PLAN (ELCP)

NOTE: *Interim End of Life Care Plans are available from the Chief RMOs office, CH2W, ICU and Palliative Care Service.*

1.   Introduction

An ELCP is a management plan that outlines what will and will not be done for the child who is dying. It presupposes that active resuscitation will not be undertaken, however the emphasis should be on the positive aspects of care. Respect, dignity and the comfort of the child will be paramount. The plan should include nursing care, be detailed and explicit and identify the:

1. Goals of treatment

2. Treatment considered appropriate

3. Name and contact number of the senior doctor responsible for formulation of co-ordinating the ELCP.

Examples of the sorts of treatment that should be defined include: the use of oxygen and the method of delivery; the use of suction for the clearance of secretions; the use of inotropes; the use of intravenous or nasogastric fluids or nutrition; the use of blood products; the use of antibiotics; and the measures to be taken for the relief of pain and discomfort (e.g. medications, nerve blocks, etc). The ELCP should state exactly what life support measures will and will not be instituted should the child deteriorate acutely e.g. oxygen and suction, but not intubation or cardiac compression. The ELCP may state either that invasive procedures and investigations are not to be performed or should explain why they are appropriate. The plan should state that organ donation has been discussed and indicate the result of that discussion, although organ donation rarely will be appropriate in the setting that acute resuscitation is not to be undertaken.

2.   Formulation of the Plan

An ELCP should be formulated for children who have an illness from which there is no prospect of recovery and for whom "life saving measures" may cause further suffering without preventing their further deterioration and death. The responsibility for formulating the plan rests primarily with the senior doctor, the child (where appropriate) and family in consultation with the clinical team (especially nursing staff, social worker and general practitioner), the Palliative Care Team and, at the request of the family, religious and/or community workers. The cultural context of the family should be considered.   Interpreters should be used in families of non-English-speaking background.   Formulation of the plan may be facilitated by a case conference.

CD: 568 V: 0.1a Reviewed April 2004	Review by: May 2007	Page 1 of 2

Reference: SCH.C.2.03

Sydney Children's Hospital	Clinical Standards and Practice Manual	ELCP Working Party
Section: 2		Effective date: 1 May 2004

3. Points of conflict

There may be disagreement between the family and the treating team(s) or within members of either group as to what constitutes appropriate care. It is imperative that any such conflict be resolved prior to the development of an ELCP.

Resolution should be reached through discussion. A second opinion may assist this process. Where resolution cannot be achieved internally, the chairperson of the SCH Ethics Advisory Committee (EAC) may be contacted at the discretion of the Senior Doctor. The EAC can provide a forum for discussion and may offer advice, but will not act as an adjudicator in disputes; nor is the advice of the EAC binding. In special circumstances, consideration may need to be given to the provision of an advocate for the child. Consideration also may need to be given to obtaining a legal opinion where the family wish to pursue treatment against the advice of the treating clinicians.

4. Distribution

The ELCP form should be filled out legibly and a copy given to the family who are encouraged to discuss it with their general practitioner and others who they consider appropriate. Do not use abbreviations on this form.

Inpatients:

For an inpatient, the ELCP should be placed in a red plastic sleeve at the front of the child's current continuation notes and a dated entry made in the continuation notes including a summary of the relevant discussions and who took part in them. The after hours medical team and the Nurse Manager are to be aware of the ELCP. The ELCP should be up-dated weekly for an inpatient.

Outpatients:

If the child is discharged from hospital, a copy of the ELCP must be given to the parents and sent to the doctors in the community who are nominated by the family to be those most likely to be involved acutely. On the ELCP, an ambulance called in an emergency may be requested to "bypass" the local hospital and bring the child to the SCH Emergency Department. The ELCP should be reviewed and dated by the managing clinician at least every 6 months.

Revision And Approval History

Date	Revision No.	Contact and Approval
1st May 2004	1.0	
29th February 2008	1.0a	Diana Alan – convert to .pdf only

CD: 568 V: 0.1a Reviewed April 2004	Review by: May 2007	Page 2 of 2

Abbreviations

ACD	Advance care directive
ACP	Advance care plan
CALD	Culturally and linguistically diverse
CEC	Clinical Ethics Committee
CPR	Cardiopulmonary resuscitation
CRELS	Conflict resolution in end of life settings [project]
DOH	Department of Health
EOL	End of life
GMCT	Greater Metropolitan Clinical Taskforce
GT	Guardianship Tribunal
HCCC	Health Care Complaints Commission
HNEAHS	Hunter New England Area Health Service
HP	Health professional
ICU	Intensive care unit
OPG	Office of the Public Guardian
SDM	Substitute decision-maker
SESIAHS	South Eastern Sydney Area Health Service
SSWAHS	Sydney South West Area Health Service

Glossary

Best interests

The notion of 'best interests' and how clinicians and substitute decision-makers apply this in decision-making has important significance both clinically and legally, especially as the notion applies to children and their care. The test for best interests is imprecise, difficult to define both clinically and legally, and remains somewhat controversial.

However, the clearest Australian legal definition of best interests is that provided by Nicholson CJ in Re Marion *(No 2)*(1992) 17 Fam LR 336. Like most legal 'tests' it works as a checklist of factors to consider in assessing best interests. The factors listed are:

(1) The particular condition of the patient which requires the procedure or treatment;
(2) The nature of the procedure or treatment proposed;
(3) The reasons for which it is proposed that the procedure or treatment be carried out;
(4) The alternative courses of treatment that are available in relation to that condition;
(5) The desirability of and effect of authorising the procedure or treatment proposed rather than the available alternatives;
(6) The physical effects on the patient and the psychological and social implications for the patient of:
(a) authorising the proposed procedure or treatment
(b) not authorising the proposed procedure or treatment
(7) The nature and degree of any risk to the patient of:
(a) authorising the proposed procedure or treatment
(b) not authorising the proposed procedure or treatment
(8) The views (if any) expressed by the carers of the patient:
(a) the guardian(s) of the patient;
(b) the relatives of the patient;
(c) a person who is responsible for the daily care and control of the patient;
(d) the patient;

to the proposed procedure or treatment and to any alternative procedure or treatment.

This list was initially drawn up in the context of sterilisation cases concerning children with disabilities but it can be adapted to the end-of-life context for both adults and children.

In addition, the NSW Law Reform Commission[1] notes the following regarding refusal of medical treatment in children.

"4.11 At common law, parents have a responsibility to provide for the maintenance, protection, and education of their children and have the powers necessary to discharge that responsibility.21 Those powers include the power to consent to or refuse medical treatment. This power is assumed to be exercised in the child's best interests, this being the overriding criterion to be applied in the exercise of parental authority. If there is any question about whether or not a parent's decision is in a child's best interests, any person who is concerned about the child's welfare may apply to a court for an order authorising appropriate treatment for the child.22....The parens patriae jurisdiction of the Supreme Court allows it to act as the final decision-maker in relation to the medical treatment of a child, even if its orders go against the parents' decision."

Consensus

A collective decision accepted and supported by all engaged stakeholders, even where their own preferences may differ.

End of Life

That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown. An 'eventually fatal condition' refers to a progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and non-malignant illness and ageing. A person has an eventually fatal condition if their death in the

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1   NSW Law Reform Commission, *Issues Paper 24, Minor's Consent to Medical Treatment*, Sydney 2004

foreseeable future would not be a surprise. The terms *eventually fatal or terminal condition* are used interchangeably.[2]

End of Life Conflict

Where disagreement has occurred as to the goals of care or treatment decisions at the end of life and where such conflict is not resolved by usual recourse to time and further discussion between the patient, their family and treating clinicians, as appropriate.

Family

For the purposes of this document the term family refers to those closest to the person in knowledge, care and affection. This includes the immediate biological family; the family of acquisition (related by marriage/contract); and the family of choice and friends (not related biologically or by marriage/ contract).[3] It may include the 'person responsible', other relatives, partner (including same sex and de facto partners), carer or close friends according to any expressed wishes of the patient. The Person Responsible has a formal substitute decision-making role on behalf of the patient under the NSW Guardianship Act 1987. The Person Responsible should be involved in planned EOL decisions, however it is prudent to include broader family in such discussions and this becomes necessary when resolving conflicts.

Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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 patients 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]

Treating Team

The multidisciplinary team of health professionals involved in the patient's management and care, including medical, nursing, allied health, social workers and counsellors, carers and spiritual advisors.

Person Responsible

The Guardianship Act establishes who can give valid consent for medical treatment to an incompetent patient aged 16 years and over. Consent of the person responsible is required in relation to provision of minor and major medical treatment. The Act establishes a hierarchy for determining who is the person responsible as follows:

- The patient's lawfully appointed guardian (including an enduring guardian) but only if the order or instrument appointing the guardian extends to medical treatment.
- If there is no guardian, a spouse including a de facto spouse and same sex partner with whom the person has a close continuing relationship.
- If there is no such person, a person who has the care of the patient (otherwise than for fee and reward).
- If there is no such person, a close friend or relative.

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2   Palliative Care Australia, *Palliative and End of Life Care – Glossary of Terms*. PCA, Canberra, 2008.
3   Canadian Palliative Care Association, *Standards for Palliative Care Provision*, June 1998

World Health Organisation's (WHO) Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes."[4]

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4   World Health Organisation n.d. Palliative Care. World Health Organisation, accessed 9.08.10

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Consultation Summary

Method

The *Conflict Resolution in End of Life Settings* Report (CRELS Report) was developed by a multidisciplinary Working Group tasked with examining the causes, prevention and management of disputes that sometimes occur in making decisions to withhold or withdraw life-sustaining treatment in dying patients. Consultation on the CRELS Report was conducted from end May till end June 2010. A cover letter from the Director-General accompanied both hard and electronic copies of the Report. It was disseminated primarily to NSW stakeholders, although viral dissemination enabled reach across jurisdictional borders. Comment was directly sought from:

- Area Health Service (AHS) Chief Executives and Chief Executives, Children's Hospital Westmead & Justice Health
- Area Health Service (AHS) Directors of Palliative Care, Intensive Care Services, Renal Services, Rehab Services, Clinical Governance, Chronic Care, Directors of Nursing and Midwifery, Directors of Social Work (and/or Social Work Heads of Department in tertiary hospitals) and the Health Language Services.
- NSW Health Clinical Ethics Advisory Panel & Area Clinical Ethics Committees (SSWAHS, HNEAHS, St. Vincent's Hospital, SESIAHS, and CHW).
- A range of academics in relevant fields.
- Professional colleges including RACP, RACS, RCNA (NSW), ANZCA, & AAGM
- A number of Departmental Branches with interest and/or activity in this area
- A number of government agencies and non-government organisations including Aged & Community Services Association (NSW), Aged Care Association Australia (NSW), AMA (NSW), Carers NSW, Clinical Excellence Commission, GP NSW Guardianship Tribunal, Health Care Complaints Commission, NSW Community Relations Commission, Office Public Guardian, Palliative Care NSW and the Ombudsman's Office.

Research, Ethics & Public Health Training Branch received 47 responses (listed at Tab 1). The CRELS Working Group considered all responses. Some amendments were agreed that appear in this Final Report.

Themes

1. General comments

Most respondents commented that the Report was comprehensive, easily readable and tackled a complex issue well. There was broad support for the thrust of the Report and its recommendations. In particular, there was support for:

1. Targeted communication skills training;
2. Best practice advice and training in managing EOL family conferences;
3. Advice about second medical opinion;
4. Advance care planning measures including improved means of identification of the substitute decision-maker (Person Responsible);
5. Development of a EOL conflict 'toolkit';
6. Improved understanding amongst health professionals of the role and scope of powers of Person Responsible and role of Guardianship Tribunal & Office of the Public Guardian in these disputes and EOL decisions generally; and
7. Improved availability and access to social work and interpreter services.

2. Specific issues

A number of specific issues were raised as either under-discussed or not identified in the Report:

- The role of General Practitioners was not adequately considered or discussed in the Report. GP NSW and other GP respondents emphasised the varied role of GPs in end of life decisions and care. This role includes "translating, supporting and bulwarking families through crisis" that may follow hospitalisation, specific skills in conflict resolution and handling difficult consultations, end of life care planning, and potentially

acting as a second medical opinion or mediator in EOL conflicts. Appropriate remuneration for GPs to undertake EOL care planning was also identified as problematic.

- The need to develop models through which mentorship could be delivered to clinicians engaged in EOL conflicts was identified, although no suggestion was made as to how and by whom.
- The need was identified for better support from hospital Managers for clinicians who are engaged in EOL conflicts, rather than then prevailing risk-management approach that occurs, at least in a proportion of cases.
- Development of an implementation strategy for EOL education & training was seen as a higher priority than development of additional specific educational resources at this time. It was thought this should include, but not be limited to collaboration with the professional Colleges.
- A potential role was mooted for the new NSW Agency for Clinical Innovation in developing advice around second medical opinion, or in progressing implementation of the clinically focussed Report recommendations more generally.
- A potential role for Bureau for Health Information in data collection and audit was identified.
- The need for Ward/Unit /Department Morbidity & Mortality meetings to include review of 'how' patients die, as well as why was noted.
- Development of minimal organisational quality markers for EOL care was seen as an important future goal.
- The need for standard terminology in end of life decision-making was reinforced.
- Potential liability concerns were identified for senior nurses or social workers initiating EOL discussions where a prognosis of dying is unclear, or where family is unaware that the patient is dying, especially in urgent or unplanned scenarios.
- An emphasis on the primacy of the patient good in resolving these disputes was argued for.
- Use of No CPR orders in the context of palliative surgery and concerns about obligations and liabilities of anaesthetists where critical cardio-respiratory instability occurs were identified. In addition, concerns were identified as to whether No CPR orders can be made in the face of persisting family demands for 'futile' resuscitation and the related obligations and liabilities.

3. Additional comments

There was strong cross-agency support from Office of the Public Guardian, Guardianship Tribunal and Health Care Complaints Commission for the recommendations and inter-agency collaboration in their implementation. This included support from HCCC for examining development of a model of mediation applicable to this context.

Some submissions sought greater definition on issues that will always require case-by-case consideration, for example as to how much consensus a clinician needs within a family in order to proceed with a plan to withdraw or withhold life-sustaining treatment. For example, can a clinician proceed with agreement from the Person Responsible alone, even if there's persistent disagreement amongst other family members?

The Clinical Excellence Commission noted the high number of recommendations in the Report. While they agreed that all address important issues, they advised that tighter prioritisation would be more likely to produce effective system response.

Some issues identified will be referred to the forthcoming NSW Health End of Life Decisions Policy Review that will be review all existing NSW Health EOL policy in the latter part of 2010, including a number of issues related to:

- No CPR order/resuscitation plans
- Advance care directives
- 'Futile' treatment

Next Steps

A number of 'Priority Areas for Action' have been developed by the Working Group in light of consultation responses. These also identify collaborative links with other policy and implementation groups, agencies and organisations. The Final CRELS Report and Priority Areas for Action have been submitted to NSW Health for consideration.

No	Name	Organisation
1.	Elena Katrakis	CEO, Carers NSW
2.	Professor Brian Kelly	Professor of Psychiatry, University of Newcastle
3.	Assoc Prof Richard Chye	Director Palliative Care SESIAHS
4.	Dr George Skowronski	Director ICU, St. George Hospital, Sydney
5.	Dr Frank Formby	Pall Care Specialist, Berry NSW
6.	Peter Cleasby	Manager, Central Coast Pall Care Service
7.	Executive Director	Community Care, Ageing, Disability & Home Care, NSW Dept of Human Services
8.	Dr Mark Nicholls	ICU, St. Vincent's Hospital NSW
9.	Prof Ron Penny AO	Senior Clinical Advisor, NSW DOH
10.	Hilda Fitzgerald	RN Aged Care Facility
11.	Assoc Professor Chris Toye	School of Nursing and Midwifery, Curtin University of Technology WA
12.	Kate Baker	Chair, Directors of Social Work in Principal Referral Hospitals
13.	Dr Jan Maree Davis	Area Director, Palliative Care Service, CHN, SESIAHS
14.	Deanne Tadros	Legal Officer, Legal & Legislative Services Branch NSW Health
15.	Alana Cooper	Nursing Executive Support Manager, St George Hospital
16.	Dr Paul Dunne	Senior Pall Care Physician, Hobart Tasmania
17.	Sandra Bailey	Research Associate, School Nursing & Midwifery, Flinders Uni, SA
18.	Alison Stevens	Executive Director Governance, Justice Health
19.	Julie Garrard	Senior Social Worker, Palliative Care, Calvary Health Care, Sydney
20.	Dr Maggie Jamieson	CEO, GSAHS
21.	Mr Stepan Kerkyasharian	Chairperson, Community Relations Commission NSW
22.	Cathy Piggot	Project Manager, Department of Nursing and Supportive Care Research, Peter Maccallum Cancer Centre, Melbourne
23.	Dr Pam Montgomery	Director, Fellowship and Standards, Royal Australasian College of Surgeons
24.	Prof Debra Thoms	Chief Nursing & Midwifery Officer, Chief Executive, Caring Together, NSW Health
25.	Jeanette Sheridan	Director Clinical Strategy, Innovation & Governance, SWAHS
26.	Professor Norelle Lickiss	Clinical Professor (Medicine) Central Clinical School, Sydney Medical School, Consultant Emeritus, Royal Prince Alfred Hospital, Camperdown and Royal Hospital for Women NSW on behalf of Dean, Medical School, Sydney University
27.	Kieran Pehm	Commissioner, Health Care Complaints Commission
28.	Mr Graeme Smith	Public Guardian
29.	Mr Terry Clout	CEO, SESIAHS (CEC, Dir Pall Care, DCS, HOD Cancer Services, DCG, DON)
30.	Raj Verma	Director, Health Services Performance Improvement Branch
31.	Kathy Williams, Gillian Lewis	Policy Officers, SA Health
32.	Melissa Cumming	CNC Cancer and Palliative Care Services Remote, Upper Mitchell and Upper Castlereagh Clusters GWAHS
33.	Anne Meller	CNC – Aged & Chronic Care, Advance Care Planning Northern Health Network POWH
34.	Dr Robert Marr	President, Dying with Dignity NSW
35.	Jan Newland	CEO, GPNSW
36.	Chris Shanley	SSWAHS Advance Care Planning Project Officer Manager, Aged Care Research Unit, Liverpool Hospital
37.	Prof Colleen Cartwright	Director, Aged Services Learning & Research Centre, Southern Cross University
38.	Tracey Osmond	Chief Executive, College of Nursing, NSW
39.	Ian Hatton	Manager, State-wide Centre for Improvement in Palliative Care
40.	Professor Kate Leslie	President, Royal Australian College of Anaesthetists
41.	Malcolm Schyvens	Acting President, Guardianship Tribunal
42.	Rick Iedema, Aileen Collier	Professor of Organizational Communication, Centre for Health Communication, University of Technology Sydney
43.	Kathy Meleady	Director, Statewide Services Development Branch
44.	Danny O'Connor	Chief Executive, GWAHS
45.	Matthew Daly	Chief Executive, NSCCAHS
46.	Dr Peter Kennedy	Acting CEO, Clinical Excellence Commission
47.	Lesley Townsend	Executive Officer, Ethics of Clinical Practice Sub-committee, SSWAHS