



The Royal Australasian
College of Physicians

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Feedback on the Australian and New Zealand Intensive Care Society *Statement on Care and Decision-Making at the End of Life for the Critically Ill*

Introduction

The Royal Australasian College of Physicians (RACP) welcomes the opportunity to provide feedback on the Australian and New Zealand Intensive Care Society *Statement on Care and Decision-Making at the End of Life for the Critically Ill*. This is an important statement which has the potential to significantly improve the care critically ill patients receive in the Intensive Care Unit (ICU).

This document outlines the feedback received on each chapter from RACP Fellows with expertise in end of life care. This includes members of the RACP End of Life Working Party and a number of Fellows who have indicated they have expertise on end of life issues and are interested in contributing to the RACP's policy work.

Please note that many of the comments provided in this document have been made by individual Fellows. These comments may not reflect a consensus agreement as the length of the statement and the short consultation period did not allow for this to be reached.

The Appendix section contains additional comments made by individual Fellows which were deemed too specific or detailed to be included in the main body of this submission.

General feedback¹

This is a very comprehensive, well referenced and well written document. The use of case examples throughout is very useful and relevant as they clearly outline key issues and suggestions to resolve them.

Much of the information contained in this document could also apply to other settings and could suitably be used by a wide range of physicians and health professionals caring for dying patients.

We suggest it may be worth considering producing some of the information in this document (e.g. Chapter 1 *Principles of end of life care*; Table 7.1. *Recommended language for communicating end of life concepts*) as short stand-alone leaflets/documents or posters that could be made available to physicians working in ICU as well as other relevant settings where appropriate.

¹ Detailed feedback from one of our palliative care physicians can be found in the Appendix.

Chapter 1 - Principles of end of life care

The use of quotes at the start of the chapter is very appropriate and provides useful context for this section. The ten principles outlined read well and provide a useful summary of the key issues physicians need to consider when caring for dying patients in ICU.

Chapter 2 – Overview of end of life care

The information provided in this chapter is very useful, comprehensive and relevant. We would suggest the following additions²:

- In section 2.2 *The patient's best interest*, last paragraph: we would suggest adding that life prolonging measures are not benign in themselves, that they can be very burdensome and as such that their use cannot be seen as "doing no harm".
- In section 2.8 *Processes after death*: we would suggest adding a further dot point as follows: "Bereavement risk assessment and appropriate bereavement plan development for key carers, family and significant others" with a reference to Chapter 9 where this topic is covered.

Chapter 3 – The ethics of end of life care

Generally this chapter is well structured and covers the key elements related to ethics for end of life care. The use of case examples also very usefully illustrates key points. Our main comments for this chapter are:

- Some sections of the Chapter seem quite long and repetitive which may impact on readability. This is particularly the case with section 3.2 *The principles of autonomy*, section 3.3 *The principles of beneficence and non-maleficence* and section 3.6 *Withholding and withdrawing therapy*. We would suggest simplifying those sections and reducing them in length to improve readability.
- We would suggest section 3.2.1 *Practical suggestions to support patient autonomy* and section 3.2.3 *Guidance regarding the principles of autonomy* are combined to improve the readability of the chapter. As they currently stand, there are some overlaps between those sections and whilst we found 3.2.1 very useful and well written, section 3.2.3 was confusing in parts.
- Section 3.5 *Cultural and religious issues* could be strengthened by including a further discussion about values which typically cannot be altered by logical argument and the need to understand there are often differences between those of the patient, their family and the doctor.
- As it is currently written, section 3.2 *The principles of autonomy* outlines a very Western approach to this concept. It would be worth considering the inclusion of a discussion about how different cultural groups approach decision-making.³
- We would suggest including section 3.7 *Sanctity of life* under section 3.5 *Cultural and religious issues* rather than as a stand-alone section as the concept of sanctity of life is closely related to religion.

Chapter 4 – Legal framework for end of life care

The review of the situation in the various jurisdictions provided in this chapter is very thorough and reflects the current and evolving situation in Australia and New Zealand. Section 4.3.1 *Lawful and unlawful actions* is particularly useful as it provides a clear statement of the legal boundaries clinicians have to operate within.

² One of our Fellows suggested adding information about Dr Ira Byock's concept of providing "best care possible". Further information has been provided in the Appendix.

³ One of our Fellows suggested including information from the Respecting Patient Choice Module on Ethics for Advance Care Planning. Relevant sections of this module have been included in the Appendix.

In addition, we have the following comments on this chapter:

- Under section 4.3.1 *Lawful and unlawful actions*, first paragraph, we would suggest rephrasing the sentence on artificial hydration and nutrition as: “Artificial hydration and nutrition via nasogastric or gastrostomy tube is included within the definition of medical therapy in this context.” This rewording removes the conditional or arbitrary sense from the statement about what is legal and what is not, rather than what clinicians may choose to do.
- Section 4.3.2 *Defining ‘euthanasia’ and physician-assisted dying’* could potentially increase confusion and may be more usefully included in Chapter 3 *The ethics of end of life care*. Chapter 4 is about what is legal, and the definitions of euthanasia and ‘Doctrine of Double Effect’ included under section 4.3.1 *Lawful and unlawful actions* are very clear. We would also suggest removing references to ‘active’ and ‘passive’ euthanasia in the quote provided under section 4.3.2. These terms are not legal concepts and we feel they may not be helpful or necessary in this context.
- We agree with the ANZICS recommendation text box on p.40 which states that intensivists should “simply describe exactly what actions are taking place”, rather than use expressions which may be misunderstood. However, we would also stress that the definition of euthanasia and its legal context are not ambiguous and that all physicians have a responsibility to know and understand these definitions and make appropriate responses when these subjects inevitably arise.
- We would suggest discussions of quality of life and futility⁴ under section 4.3.3. *Concepts forming the basis of end of life decisions* may be better placed in the ethical discussion in Chapter 3 as neither are legal entities and their inclusion in this chapter may lead to confusion.

Chapter 5 – Advance care planning

Overall, this chapter provides good coverage of the main points related to advance care planning and the inclusion of section 5.3 *Resuscitation plans* is very useful.

Our main comment on this chapter is that it focuses on the importance of undertaking advance care planning well in advance of admission to ICU (e.g. information about the role of GPs on p.47 and 48) and whilst this information is useful, it may not be so readily relevant to the key audience for this document (doctors working in ICU). We would suggest it may be better presented via a list of dot points or guidance as to what is effective advance care planning, what physicians should ask or look for, and a brief summary of the types of approaches. This would assist doctors working in ICU in feeling more comfortable following up what may have been discussed and documented previously for a given patient.

Chapter 6 – End of life care and the intensive care unit

Overall, this chapter is well structured, reads well and includes relevant information. We would like to make the following suggestions:

- Under Section 6.1 *Admission criteria for intensive care*, last sentence of first paragraph on p.54: We agree that there is no place for unilateral decision-making or for offering a menu of treatment options. In addition, we feel there is a need to acknowledge that the patient’s family is not trained in medicine, whereas physicians are. Therefore it may worth adding that the doctor should be able to objectively

⁴ Further information related to the concept of futility has been provided by one of our Fellows, their comments are included in the Appendix.

provide the "best treatment option" or a "recommended treatment option" to the family and that this should also include a "comfort only" option.

- ANZICS recommendation on p.57: we would suggest adding the following recommendation: "ICU staff should have the skills to prognosticate on a patient's overall clinical condition and on the likelihood of success of the various treatment options."

Chapter 7 - Language, communication, consensus building and documentation

The information provided in this chapter is very useful, comprehensive and relevant. We found Table 7.1 *Recommended language for communicating end of life concepts* very useful. It is a practical resource which is easy to read at a glance and therefore ideal for busy doctors. We would recommend considering producing a stand-alone fact sheet with this information which could be used as a teaching tool. As an aside, we note that this table is of relevance to physicians working in other settings apart from ICU.

In addition, we have the following comments on the content of this chapter:

- Section 7.4 *Planning and conducting an effective family meeting*, the fifth dot point outlines that the medical team should always involve the intensivist and the bedside nurse; it goes on to mention others who may be included and warns against 'crowding out' the family or patient. While we agree this should be taken into consideration, we feel it is important for senior clinicians to include, and even insist, on the presence of junior doctors at these meetings where suitable. In appropriate cases, the most senior intensive care doctor should assess the opportunity for a registrar/fellow level doctor to conduct the meeting with visible back up. This permits a valuable meeting for the family and at the same time, provides a real-life mentoring opportunity for the junior doctor. Currently, many doctors often reach consultant level having seldom conducted a sensitive family meeting where they have been observed and mentored and debriefed. This means the best learning they receive is by trial and error and ICU provides generous opportunities to change this.
- Section 7.6 *Using translators and cultural brokers for end-of-life discussions*: One of the commonest errors when using an interpreter is that doctors conduct the conversation with the interpreter rather than the patient/carer/surrogate. It would be worthwhile to underscore the point that at all times during the meeting, the doctor's focus/eye contact should be on the patient/carer. The doctor should say 'I want you to tell me what your father would have wanted to do in this situation', rather than 'I want you to ask her what her dad would do' or 'Tell me how you are feeling today' rather than 'Ask her how she is feeling'. One suggestion would be to include a short language table similar to Table 7.1 to pick up on some of these points.
- It would also be helpful to stress that an interpreter is merely the conduit for the doctor-patient conversation and it would also be helpful to include a reminder about allocating twice as much time with an interpreter and being extra patient and conscious that the level of complexity is significantly increased when using an interpreter, to allow the patient to truly absorb information.

Chapter 8 – Managing conflict

This chapter is well laid out and includes comprehensive information about how to manage a range of conflicts with regard to end of life care in the ICU.

We have a couple of suggestions:

- It would be useful to mention the possibility of requesting an ethics committee opinion as an additional mechanism for conflict resolution between teams of practitioners under section 8.2.1 *Achieving medical consensus*. An ethics committee opinion, where available, can be a useful way of capturing and formulating physicians' concerns and distress regarding problems in prognosis, treatment and withdrawal of treatment. This can be useful if there is significant disquiet, and can augment and enhance questions with may involve legal issues. Ethics committee opinion can also be used in conjunction with a second opinion, and is not always solely a medical opinion, but can incorporate legal, nursing, and lay perspectives.
- Under section 8.5.1. *Personal threats*, we would recommend rephrasing the last sentence of this paragraph. As it is currently written, it focuses on female doctors only and on "people from some cultural backgrounds" which may be perceived as discriminatory. We suggest the sentence should be made more general as personal threats or aggressive behaviours may happen regardless of cultural backgrounds and any member of the medical team may feel threatened: "In some cases, it may be necessary to strongly support or replace members of the medical team if they feel threatened".

Chapter 9 – Care of the dying patient, their family and the medical team

Overall, this chapter provides comprehensive information about the care of the dying patient, their family and the medical team. In addition, we have the following comments⁵:

- Under section 9.1 *Overview*, we would suggest rephrasing this statement as: "Clinicians should aim to focus on supporting all people involved in the case [...]"
- Under section 9.2.1 *Providing care while the patient is dying*, paragraph 1, line 4, we would suggest adding 'alone' after palliative care as palliative care/supportive care can and should be provided well before the terminal stage of an illness.
- Under section 9.2.1 *Providing care while the patient is dying*, paragraph 2, first line, we would suggest rephrasing to: "Intensive care will often be the location where life prolonging treatment for critically ill patients is being withheld or withdrawn".
- Under section 9.2.1 *Providing care while the patient is dying*, we would recommend adding a further dot point: "what are the patient's requirements for relieving the distress caused by dyspnoea?"
- Under section 9.2.2 *Palliative intervention, Non-pharmacological interventions*, we would recommend adding the following words to the seventh dot point after mouth care: "eye care, skin care, bowel & bladder care"
- Under section 9.2.2 *Palliative intervention, Non-pharmacological interventions*, we would recommend adding the following words to the eighth dot point after respiratory supports: "and implanted defibrillators". We also suggest adding the following dot point straight after: "instituting appropriate observation and monitoring schedules to maximise patient comfort and discussing these with the family and significant others"
- Under section 9.2.2 *Palliative intervention, Pharmacological interventions*, first paragraph on p.88, we would recommend adding "via an appropriate route" at the end of the first sentence.
- Under section 9.2.2 *Palliative intervention, Site of death*, we would like to stress that it is important to know patient preferences about 'Preferred Place of Care'. If home

⁵ Additional comments from one of our palliative care Fellows have been included in the Appendix.

death is wanted and feasible then the Community Palliative Care Team should be involved to ensure "best care possible" is provided to patients and their families in the setting of the patient's choice. Where home is the 'Preferred Place of Care' and cannot be provided then the dying should occur in as homely an environment as is possible with family and significant others present.

- Under section 9.3.2 *Care of the family and significant others during grief and bereavement*, we suggest rewording the second sentence of the first paragraph to: "Grief is the psychological reactions experienced in anticipation or after a loss [...]"
- Under section 9.3.3 *Post-death follow-up care and referral*, first paragraph, we would suggest adding the following risks to the list of risk factors: "past history of a mood disorder, recent other significant losses or previous history of prolonged grief reactions after any losses." We would also suggest adding the following paragraph to this section: "Individualised bereavement care plans should be developed and documented for significant family members and others based on bereavement risk assessments".

Chapter 10 - Special situations and specific diagnoses

The information provided in this chapter is very useful, comprehensive and relevant. Our only suggestion would be to add "even if the family do not agree or accept their loved one's directive" in the last paragraph under Section 10.2.1.

Chapter 11 - Infants and children

The Paediatric & Child Health Division of the RACP has released a position statement on *Decision-Making at the End of Life in Infants, Children and Adolescents* in 2008⁶ and we feel it would be valuable to review and reference it in this Chapter. Another important statement to consider is *Withholding or Withdrawing Life Sustaining Treatment in Children: A framework for Practice*, Second Edition, May 2004⁷ from the Royal College of Paediatrics and Child Health (RCPCH).

The range of topics covered in this chapter is comprehensive and overall the information provided is useful. We have a number of suggested changes which relate to rewording certain sections of the chapter and adding relevant information to improve its readability⁸:

- Under section 11.2 *Issues for end of life care decision making for infants and children*, we would suggest rewording the sentence starting on line 7 to "Several clinicians who know the child from previous admissions express the view that admission to intensive care would be in the child's best interests. Others argue that [...]"
- Under section 11.2 *Issues for end of life care decision making for infants and children*, under *Resolution* first dot point, we would recommend changing the wording to: "Decisions to limit treatment for infants and children are based on the same standard as adults".
- Under section 11.2 *Issues for end of life care decision making for infants and children*, under *Resolution*, we would suggest rewording as follows: "The question:" "What would you do if this were your child?" does often arise, and should be

⁶ This position statement can be found via this link: <https://www.racp.edu.au/index.cfm?objectid=B5603385-D3A3-F3B4-7159013AE33D4697>

⁷ This document can be accessed via this link: http://www.gmc-uk.org/Withholding.pdf_40818793.pdf

⁸ Additional comments from a Paediatric & Child Health Division Fellow are included in the Appendix.

considered prior to talking to the parents [...] On the other hand, answering the question honestly may improve trust within the relationship and should not be avoided.”

- Under section 11.2.1 *Should decisions to limit treatment for children or infants be based on different standards than those for adults?*, we would suggest substituting ‘adults’ for ‘older people’ in the first sentence.
- Under section 11.2.2 *What is the role of parents in decision making for children and infants?*, first paragraph, we would recommend rewording to: “While families are important in end of life decision making for most patients, they are central in making decisions for children. Parents will usually [...]”
- Under section 11.2.3 *How certain can you be about the prognosis?*, first paragraph, we would recommend adding the following sentence: “Where uncertainty exists with regard to the value of a treatment, the parents’ values and views play an important role in determining whether or not it ought to be given, provided they have been informed about all potential benefits/burdens of the treatment.”
- Under section 11.2.4 *Under what circumstances is it ethical to limit or withdraw life-sustaining treatment?*, we would recommend referring to the RCPCH framework for practice on withholding or withdrawing life sustaining treatment in children. In its summary, this document includes five situations where it may be ethical and legal to consider withholding or withdrawal of life sustaining medical treatment as follows:
 - 1) **“The ‘Brain Dead’ Child.** *In the older child where the criteria of brain stem death are agreed by two practitioners in the usual way it may still be technically feasible to provide basal cardio-respiratory support by means of ventilation and intensive care. It is agreed within the profession that treatment in such circumstances is futile and the withdrawal of current medical treatment is appropriate.*
 - 2) **The “Permanent Vegetative’ State.** *The child who develops a permanent vegetative state following insults, such as trauma or hypoxia, is reliant on others for all care and does not react or relate with the outside world. It may be appropriate to withdraw or withhold life-sustaining treatment.*
 - 3) **The ‘No Chance’ Situation.** *The child has such severe disease that life-sustaining treatment simply delays death without significant alleviation of suffering. Treatment to sustain life is inappropriate.*
 - 4) **The ‘No Purpose’ Situation.** *Although the patient may be able to survive with treatment, the degree of physical or mental impairment will be so great that it is unreasonable to expect to bear it.*
 - 5) **The ‘Unbearable’ Situation.** *The child and /or family feel that in the face of progressive and irreversible illness further treatment is more than can be borne. They wish to have a particular treatment withdrawn or to refuse further treatment of the medical opinion that it may be of some benefit.”*
- Under section 11.2.4 *Under what circumstances is it ethical to limit or withdraw life-sustaining treatment?*, we would recommend rewording the second sentence in the second paragraph to: “We should not impose treatment that we do not feel is medically indicated.”
- Under section 11.2.6 *What if consensus can’t be reached*, second sentence in the first paragraph, we would suggest rewording this sentence as follows: “Parents can usually be relied upon to do what they feel is best for their child. However, it is not always appropriate or necessary to follow parents’ requests”.
- Under section 11.2.6 *What if consensus can’t be reached*, second paragraph, we would suggest the following rewording for the first sentence: “When the medical team

agrees that life sustaining treatment clearly benefits a child, it should be provided even if the parents disagree.”

- Under section 11.2.6 *What if consensus can't be reached*, third paragraph, we would suggest removing 'admittedly' from the first sentence.
- Under section 11.2.8, *Use of the terms DNR, NFR or AND*, we would recommend the following rewording of the second paragraph: “It is essential that a discussion takes place with the parents about which specific interventions are and are not appropriate after an analysis of 'benefits versus burden'. This should include a detailed discussion comprising interventions [...]”
- Under section 11.2.8, *Use of the terms DNR, NFR or AND*, we would suggest the following rewording of point 1.: “Children do not usually have the capacity to communicate their future treatment choices”
- Under section 11.3.1 *Supporting parents during withdrawal of life-sustaining treatment*, we recommend rewording the second sentence of the first paragraph as follows: “If their child is to be extubated, find out whether the parents want this to happen while they are cuddling their child or with their child on the bed”.
- Under section 11.3.1 *Supporting parents during withdrawal of life-sustaining treatment*, we suggest rewording the fourth sentence of the first paragraph as follows: “Prepare them for the possibility that their baby or child may develop a gasping breathing pattern shortly before death (agonal gasping). Many parents find this very distressing, and it is important to reassure them that this is not a sign of pain or distress.”
- Under section 11.3.2 *Practical support for parents around the time of death of their child*, we would recommend rewording the third sentence of the first paragraph as follows: “Additionally, they should be given the opportunity to continue (they do not usually stop their parent role even whilst their baby/child is dying) their role of 'caring parent' and involvement in their child's care. A single room should be provided wherever possible, and visiting restrictions for other family members and friends liberalised. Some parents may wish to hold their child, lie in the bed with her or him or in a bed close by.” We would also suggest adding this sentence to this paragraph: There is no legal reason why parents may not take their baby out of the hospital after death. For the protection of the parents and to avoid any misunderstandings appropriate documentation should be given to the parents.

Chapter 12 – Organ and tissue donation

We have no specific comments on this chapter.

Chapter 13 - Evaluating the quality of end of life care

This chapter provides a useful outline of an evaluation process for end of life care which involves systematic and regular measurement of performance compliance with elements which are important or vital to the delivery of best practice end of life care.

The chapter focuses on obtaining qualitative information from family members about their experience of their relatives' end of life care, which is key to evaluating the quality of end of life care. However, we would also recommend including information about the type of quantitative data which is or can be collected in ICU for the purpose of evaluating the quality of end of life care. Examples of relevant quantitative data to consider have been included in the Appendix.

APPENDIX – Additional comments from individual Fellows

General feedback

Information from a palliative care Fellow:

“This is an excellent document that I find hard to fault.

It is consistent in its thoughtful wise guidance for the difficult situations that are likely to arise in the care of critically-ill patients in Intensive Care situations.

I have been particularly impressed by the repeated use of illustrative cases teased out for a presentation of the issues involved followed by a suggested sensible resolution.

The document faces uncomfortable situations squarely – such as disagreement between consultants, and is balanced and practical in its suggestions.

As a palliative care physician I was pleased to see the list of the components of a good death. Preferred site of death is listed, and needs to include home. Because active support of respiration and cardiac function is so common a part of Intensive Care, and withdrawal usually means quite rapid decease, transfer to home from ICU is unlikely. However, there are many other cases with illnesses close to ‘critical’ and ‘terminal’ for which transfer to home can be entertained and sometimes managed very successfully.

The document carries a clear message that many of the issues discussed come to consideration too late if they are faced only in Intensive Care. Advance Directives, Advance Care Planning, Talking about Death are all opportunities for individuals and families to be ready, as far as they are able, for possible unwelcome futures.

There is a recurring problem for the very elderly housed either at home or in an Aged Care Facility. A sudden decline, met with inadequate assessment or consideration, leads to emergency referral. This may be followed by possible pressure for Intensive Care Admission without hope of recovery to previous function. Awareness of such stories needs to be part of growing old, so that we are prepared to avoid unhelpful hospital admission.

The cautious, respectful and unhurried management adopted in the situations described is a model of what should be a key part of all taxing and contentious medical practice. Discussion of these end-of-life issues needs to be part of more everyday medical, even community, life, so that all of us come to emergency situations with some preparation for the decisions we may have to face.”

Chapter 2 – Overview of end of life care

Information from a palliative care Fellow:

In section 2.2 – *The patient’s best interest*, second paragraph: this section could be improved by providing further contextual information to qualify this statement. Our suggestion would be to make reference to Dr Ira Byock’s concept of providing “best care possible”⁹ which focuses on delivering impeccable holistic symptom assessment and

⁹ For further information about this concept, please visit: <http://www.dyingwell.org/>

multidisciplinary team management, rather than on the negative of withdrawing and withholding treatments.

Chapter 3 – The ethics of end of life care

Information from the Respecting Patient Choice Module on Ethics for Advance Care Planning:

“There is no single way that people choose to approach how decisions should be made if they become unable to make their own healthcare decisions.

For some people, their main concern is their right as an individual to exercise their autonomy. Their focus is likely to be on truth-telling, informed consent and completing advance care directives outlining their specific treatment wishes.

For other people, their main concern is their relationships. The person may be concerned with how their decisions will affect these relationships rather than what the decisions are. There may be less focus on truth-telling and preferred types of treatments or outcomes. They may consider the effect of their decisions on family members or may prefer family members to make decisions for them.

Each person has their own preferences on decision-making and these preferences should not be assumed. There will be variation between and within cultures. These preferences influence how a person makes a decision and their motivations in choosing to do advance care planning. For example, a person who prefers autonomy may complete advance care planning to maintain control over their own body at times in the future where they do not have capacity for decisions. A person who prefers a relationship approach may complete advance care planning to reduce the burden on their family.”

Source: Respecting Patient Choice Module on Ethics for Advance Care Planning

Chapter 4 – Legal framework for end of life care

Further information on the concept of futility from one palliative care Fellow:

In my view, futility is not “highly subjective” or ambiguous and does not imply worthlessness. Rather it can be a most helpful concept for assisting clinicians in the end of life situation, bringing some objectivity to decisions around the withdrawal and withholding of treatment. The equation of “0 out of 100 equals futile” can be a helpful guide. As always, it is the duty of clinicians to speak sensitively to patients and families to minimise uncertainty and unnecessary distress.

Futility while not a legal term is a definable entity. The excellent essay of Scheidemann et al (Annals of Intern Med 1990; 112; 949-954) provides a working definition:

“ When physicians conclude,(either through personal experience, experiences shared with colleagues, or consideration of published empiric data) that in the last 100 cases (sic) a medical treatment has been useless, they should regard that treatment as futile.”

The discussion distinguishes futility from such concepts as theoretical impossibility, minimal probability and extreme rarity. Physicians are advised to distinguish between an effect, which is limited to some part of the patient's body, and a benefit, which appreciably improves the person as a whole. Treatment that fails to provide the latter, whether or not it achieves

the former, is 'futile'. The need to be aware of potential exceptions, to consult with colleagues and to obtain informed consent, are duly acknowledged.

Chapter 9 – Care of the dying patient, their family and the medical team

Additional comments from one palliative care Fellow:

Whilst this document focuses on critically ill patients, it is important to highlight that the majority of decisions about withdrawing potentially life-prolonging measures tend to be made well before patients are critically ill and requiring extraordinary measures in an ICU.

Appropriate observation schedules need to reflect outcome measures and modes of assessment consistent with the patient's cognitive status.

Discussions about ongoing hydration and nutrition versus comfort cares alone are vital to have up-front with patients, their families and significant others.

It is important that clearly documented individualised Terminal Care Plans are developed, proactive anticipatory prescribing via an appropriate route occurs, observation and monitoring schedules are put in place and 'goals of care' are openly discussed and agreed to amongst all parties: patients (where still possible), family & significant others and members of the treating team. This will ensure "best practice" terminal care is provided, measured and documented and that meaningful mortality audits can then be used to continuously improve the quality of "care of the dying" being provided in any unit.

Comments specific to section 9.2.2 *Palliative intervention*:

- Under section 9.2.2 *Palliative intervention*, *If death is not imminent*, first paragraph, third line, suggestion to add "and proactively charted PRN via an appropriate route" after "Pharmacological measures should always be available"
- Under subsection *Pharmacological interventions* first paragraph on p.88, please note subcutaneous routes can be just as efficacious as intravenous routes although they may be more useful outside an ICU setting.
- Under subsection *Drug doses for palliative care and symptom relief*, p. 89, suggestion that these drug guides should include subcutaneous routes and that PRN frequencies should be 1 to 2 hourly.
- Under subsection *Drug doses for palliative care and symptom relief*, p. 89, hyposcine butyl bromide should also be added @ 20mg sc q2hrly PRN
- Under section 9.3.3 *Post-death follow-up care and referral*, suggest adding a new paragraph to this section which states that "Individualised bereavement care plans should be developed and documented for significant family members and others based on bereavement risk assessments".

Chapter 11 - Infants and children

Additional comments from a Paediatric & Child Health Division Fellow

In section 11.1 *Overview*, the first paragraph of the statement in this section is too emotive and could create confusion. Suggestion of using the following quote by Professor David Baum instead, it gives a valuable overview of what end of life care decisions in children is all about

“Paediatricians are vocationally committed to promoting children’s health, treating their illnesses and saving their lives. There are, however, occasionally tragic circumstances in which, jointly with the child’s family, and where appropriate with the child her or himself, we are forced to wrestle with dreadful choices. Sometimes it is necessary to come to the conclusion that for an individual child- who might be a premature baby, a toddler, a child at primary or secondary school, a teenager or young adult- the more humane path is one of palliation rather than a continuation of life saving treatment. To so resolve is profoundly difficult, challenging the doctor and all members of the Health Care Team with issues of conscience and internal conflicts. Nevertheless our professional responsibilities do not allow us to walk away from such difficulties.”

Source: Professor David Baum, RCPCH, September 1997, ‘Withholding or Withdrawing Life Sustaining Treatment in Children: A framework for Practice, Second Edition, May 2004, RCPCH

Under section 11.3.2 *Practical support for parents around the time of death of their child*, suggest adding the following information after the second paragraph: “Many parents are too shocked and distressed to think about creating mementoes at the time of loss. In most neonatal units, staff are very good at producing and collecting mementoes such as hand and footprints and samples of hair. ‘Heartfelt’ is an Australian wide volunteer organisation of professional photographers who take photos of terminally ill infants and children as a gift to their families.”

Chapter 13 - Evaluating the quality of end of life care

Additional comments from a palliative care Fellow

The selection of the menu of key elements is a matter for the ICU profession, perhaps modified by practitioners in individual units to address local circumstances. Published and validated existing pathways and measurement tool can be incorporated in part or in whole, but the final choice of which elements are measured should be agreed within the specialty.

The selected elements for evaluation should accurately reflect what happens within the unit at patient level. Grouped data such as in Part A below should be sufficiently precise to identify departures from accepted service provision profiles. The appropriateness of highly intense and sustained interventions for younger salvageable patients and the inappropriateness of prolonged intervention for very elderly persons with multi-organ system failure should be equally identified.

Of its nature ICU practice provides a great deal of quantitative data and readily defined and contained events which facilitate performance evaluation. Likewise, it is understood that evaluation will occur within the complexity and human stresses of ICU practice and must not impede or aggravate the care delivered. A requirement for meaningful investment in data identification, collection, analysis and communication is acknowledged. The benefits of evaluation in improved clinical outcomes, in patient, family and staff satisfaction and in reduced costs, are well worth the investment.

The outline provided here identifies the necessary components for assessment of a clinical service. The details are not listed as these are the prerogative of the specialty or practice in question and must be acceptable to a majority of professionals within that practice.

It is also a key principle that the results of such evaluations are presented in the first instance to the clinicians who practice in the given service. There are additional benefits from sharing data and outcome experiences and establishing benchmarks which themselves become subject to review. However freedom to assess performance of one's own unit or service in a secure setting should be expected.

Two protocols for examining specific elements of care are provided, as examples only to illustrate a capacity to measure the non-technical elements of end of life care in ICU.

Key Elements

A. Demography and utilisation data

Who is dying in ICU

Age, sex, diagnoses, referral patterns etc

What are the service descriptors

LOS, procedure/interventions, time on ventilator, outliers, costs etc

Patient care elements

Patient preferences, family communication, palliation, pastoral, bereavement etc

How do we compare

Benchmarking with peer services and regional/national data

B. Measuring performance

Establish list of elements for best practice EOL care: inclusion and exclusion items

Regular audit for rates of compliance with criteria

Review results against prior performance and peer performance

Complete the quality cycle and repeat

Example 1

PACE record

The PACE record is brief, on two sides of paper. It first asks for assessment of five aspects within 24 hours of admission to ICU:

- a) Family details: key relationships; children; guardianship issues; vulnerable adults
- b) Social details: financial concerns; religious/spiritual needs; language/cultural needs; transport/parking needs; other needs
- c) Patient preferences: previously expressed wishes; preferred place of care; presence of advance directive / statement or will

d) Communication and information: patient / NOK awareness of situation; people to be given information; explanation of ICU

e) Any other issues: which patient, family or staff feel is important.

(The next section of PACE gives space for a continuing assessment of communications and responses around these questions).

Source: Higginson et al. BMC Medicine 2013, 11:213

<http://www.biomedcentral.com/1741-7015/11/213>

Example 2:

Table 5. Selected Outcomes for Evaluation of ICU Palliative Care Consultation Screen

What proportion of ICU patients meeting the criteria are actually identified for referral?

Of the patients identified as appropriate for palliative care consultation, what proportion is actually referred?

What proportion of the referrals are actually completed by the palliative care consultation service?

What is the time interval between referral and consultation?

Which criteria are capturing the largest groups of patients and generating the most referrals?

What is the impact of screening on ICU workflow?

What is the impact of screening on palliative care workflow?

What is the impact on ICU staff morale/moral distress?

How have patients/families reacted to the screening process?

Debriefing on impact of ICU Palliative care consultation screen:

Has the quality of care been improved, worsened, or remained unaffected by implementation of the palliative care consultation initiative?

Could the same results have been achieved without specialists' input?

What adjustments could be made to enhance the experience for patients, families, and clinicians?

- Mortality rate in ICU
- Epidemiology of deaths in ICU- demography and morbidity
- Intervention profiles
- Outlier LOS
- Prolonged ventilation
- Criteria for unstable pain- incidence and duration
- PC consultant interventions

- Family meetings
 - on admission
 - ongoing
 - follow-up
- Agenda of family meetings
- Treatment withdrawal and NFR

Source: Nelson JE. Curtis JR. Mulkerin C. et al. Improving Palliative Care in the ICU. (IPAL-ICU Project Advisory Board). *Critical Care Medicine*. 41(10):2318-27, 2013 Oct.