



**Queensland
Government**

Implementation Guidelines

**End-of-life care:
Decision-making for withholding and
withdrawing life-sustaining measures
from patients under the age of 18 years**

Part 1

**Legal Framework, Clinical
Considerations and Decision-
making Framework**

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EXECUTIVE SUMMARY

These guidelines relate to the decision-making for withholding and withdrawing life-sustaining measures from patients under the age of 18 years. These complement and are integrated with similar guidelines that exist for patients aged over 18 years in the jurisdiction of Queensland.

The guidelines have three main sections of focus –

1. Clinical Considerations
2. Legal Considerations
3. Ethical Considerations

Issues related to communication are also included at the end of the guidelines.

Queensland Health has six fundamental principles which apply to withdrawal of life sustaining measures in children. These are:

- Principle 1:** There must be respect for life and acknowledgement that death is an inescapable part of life.
- Principle 2:** All decision-making must meet the standards of good medical practice.
- Principle 3:** For adult patients, all decision-making must respect the right to know and choose.
- Principle 4:** For patients under the age of 18 years, all decision-making must be in their best interests.
- Principle 5:** All efforts must be made to obtain the appropriate consent through a collaborative approach.
- Principle 6:** There must be transparency in and accountability for all decision-making.

Further key principles relating to infants, children and young people which are highlighted in these documents are as follows:

1. There is no significant ethical difference between withdrawing (stopping) and withholding (not providing) treatments, given the same ethical objective.
2. Optimal ethical decision-making concerning children requires:
 - open and timely communication between members of the health care team and the child and family
 - respecting their values and beliefs and
 - the fundamental principles of ethics and human rights.
3. Parents may ethically and legally decide on behalf of children who are unable, for whatever reason, to express preferences, unless they are clearly acting against the child's best interest or are unable, unwilling or persistently unavailable to make decisions on behalf of their child.
4. The wishes of a child who has obtained sufficient understanding and experience in the evaluation of treatment options should be given substantial consideration in the decision making process.

5. The antecedent wishes and preferences of the child, if known, should also carry considerable weight given that conditions at the time for action match those envisaged in advance.
6. In general, resolution of disagreement should be by discussion, consultation and consensus.
7. The duty of care is not an absolute duty to preserve life by all means. There is no obligation to provide life sustaining treatment if:
 - its use is inconsistent with the aims and objectives of an appropriate treatment plan
 - the benefits of that treatment no longer outweigh the burden to the patient.
8. It is ethical to withdraw life sustaining treatment if refused by a competent child; or from children who are unable to express wishes and preference when health care team and parent/carers agree that such treatment is not in the child's best interests.
9. A redirection of management from life sustaining treatment to palliation represents a change in beneficial aims and objectives and does not constitute a withdrawal of care.
10. The range of life sustaining treatments is wide and will vary with the individual circumstances of the patient. It is never permissible to withdraw procedures designed to alleviate pain or promote comfort.
11. There is a distinction to be drawn between treatment of the dying patient and euthanasia. When a dying patient is receiving palliative care, the underlying cause of death is the disease process. In euthanasia, the intended action is to cause death.
12. It follows that use of medication and other treatments which may incidentally hasten death may be justified if their primary aim is to relieve suffering. The practice of euthanasia in Australia is prohibited, and this is reflected in all Queensland Health documentation around end-of-life decision-making.
13. Legal intervention should be considered when disputes between the health care team, the child, parents and carers cannot be resolved by attempts to achieve consensus.

Finally, a concise summary of these guidelines and the use of the Paediatric Acute Resuscitation Plan can also be found in the "Quick Guide to Completing a Paediatric Acute Resuscitation Plan (PARP)" which is attached to the PARP. [Link to "Quick Guide"]

PART 1

INTRODUCTION

Because of their vulnerability, restricted autonomy, emotional significance and potentiality, children are afforded special status in society. The medical care of children raises many complex clinical, legal and ethical issues, primarily because children are generally considered not to be capable of expressing autonomous informed preferences. In almost all circumstances, the responsibility falls to the parents who have wide-ranging moral, social and legal obligations for upholding and protecting their child's best interests. However, this parental responsibility is not absolute. Since the introduction of international and national laws and conventions recognising and protecting the rights of children, children are also considered beings in their own right.¹ This means that medical decisions made by parents can be overturned if it can be established they are clearly not in the best interests of the child.

In order to avoid potential conflict situations, the objective for optimal clinical decision-making for children must be through an open collaborative process that upholds the standards of good medical practice, meets the legal framework, and is based on clear ethical principles. While *prima facie* the goals contained within such an objective appear reasonably straight forward, complex ethico-legal arguments such as those contained in court judgements continue to confirm that this is not the case. A plethora of national and international literature, including policies and guidelines has also attempted to clarify each of these goals and the relationship between them. While some of the guidance can apply in multiple settings for some paediatric patients, other guidance applies in all clinical settings, but only selectively in Australia. Some commentators even argue that four bioethical principles as proposed by Beauchamp and Childress (2006) (ie. beneficence, non-maleficence, autonomy and distributive justice) cannot be equally applied to clinical decision-making for children.² With all this complexity where then, does this leave health teams specialising in the treatment of children as they tenuously navigate the challenging, and sometimes contradictory ethico-legal decision-making pathways for gravely ill children?

The consistent theme, reflected in the laws and ethical principles is that all decision-making must be in the best interests of the child. Reasonable judgments of the burdens, benefits, prospective quality of life and clinical efficacy are also part of the decision-making framework. In that most difficult area where decisions to withhold or withdraw life-sustaining medical treatment for those under 18 are required, a 'family-centred' model of care is proposed.³ Such an approach still retains a clinical and moral focus on the child, but also recognises the family, acknowledging its strengths and limitations, appreciating its uniqueness and explicitly including the family in a multi-disciplinary collaborative team responsible for medical treatment for and care of the child.

¹ UNICEF website. Convention on the rights of the child. <http://www.unicef.org/crc/>

² Baines, P. (2008). Medical ethics for children: applying the four principles to paediatrics. *J Med Ethics* 2008; 34: 141-145.

³ American Academy of Pediatrics (2003).

This guidance is in two parts: Part 1 covers clinical and legal considerations as well as providing a decision-making framework and information about dispute resolution; Part 2 provides ethical considerations and communication strategies relevant to dying children.

Policy Statement

Queensland Health recognises that there are significant and complex clinical, ethical and legal considerations in making decisions around life-sustaining measures, even when patients have the capacity to make the decision themselves. All decisions to provide, withhold or withdraw life-sustaining measures must comply with the standards of good medical practice, be clearly documented, and based on legal requirements for consent from the patient or their substitute decision-maker/s.

This policy is supported by the four bioethical principles of patient autonomy; beneficence, non-maleficence and distributive justice. The scope of this policy covers all Queensland Health facilities and includes all patients diagnosed with a life-threatening illness or condition. This policy replaces the previous version of the policy which applied only to adult patients.

Decisions to withhold or withdraw life-sustaining measures must also consider diagnostic and prognostic uncertainties, the potential benefits and burdens of the proposed treatment plan, having regard to the patient's best interests and quality of life.

There must also be an emphasis on advance care planning. This means initiating resuscitation planning as early as practicable, minimising the need to determine a patient's wishes (where this applies) through their substitute decision-maker/s in a crisis-driven situation. Advance care planning discussions can be held with all patients; including children and young people, where it is determined they are capable of contributing to the decisions.

In meeting the standards of good medical practice, doctors are not obliged to offer nor provide medical treatment considered clinically inappropriate. This must be balanced with providing sufficient information to patients and/or their substitute decision-makers in order to make an informed decision. Demands made by patients or families for medical treatment that on the balance of probabilities would be considered burdensome or harmful, and offer limited or no benefit to the dying patient, need not be acceded to. However, where there is doubt or uncertainty in prognosis or outcomes of the proposed treatment, second opinions must be obtained from a more experienced clinician or consultant, and the clinical decision must favour life. In such circumstances it would be expected that a collaborative decision-making process is followed involving the health care team, ensuring that at all times the patient's best interests are upheld and consent is obtained where required.

For patients under the age of 18 years, all decision-making must be in their best interests, including decisions they are competent to make for themselves. It is Queensland Health's policy position that all patients under the age of 18 years should be afforded the opportunity to be involved in health care decision-making, commensurate with their competency, level of maturity and willingness to participate. While it is acknowledged that many older children and adolescents may be competent to consent to (positive) medical treatment that saves their life and health, decisions to withhold or withdraw medical treatment (negative) that will ultimately result in the death of the child or young person must be made by the parent/s or person/s with parental authority. Because of the gravity and seriousness of decisions around life-sustaining measures, for patients under the age of 18 years, parents or person/s with parental authority should always be involved in the decision-making process, irrespective of the child's understanding of the situation and level of maturity.

Queensland Health's principles for decision-making about life-sustaining measures:

- Principle 1:** There must be respect for life and acknowledgement that death is an inescapable part of life.
- Principle 2:** All decision-making must meet the standards of good medical practice.
- Principle 3:** For adult patients, all decision-making must respect the right to know and choose.
- Principle 4:** For patients under the age of 18 years, all decision-making must be in their best interests.
- Principle 5:** All efforts must be made to obtain the appropriate consent through a collaborative approach.
- Principle 6:** There must be transparency in and accountability for all decision-making.

BACKGROUND

Advances in medicine and technology have increased our ability to sustain life beyond the point at which survival, or survival with a reasonable quality of life, would historically have been possible. Such advances in medicine and biomedical technology have created the possibility for medical treatment to be continued beyond the point at which it offers any benefit to the patient and may prolong suffering, and indeed the dying process. This new capability brings with it considerable clinical, moral, socio-cultural, legal and economic responsibilities - responsibilities that force us as a society to challenge the goals of medicine and the values of those who provide care in our hospitals and care facilities. While issues about those dying in our community arise in many settings, they are, perhaps, most challenging in paediatric settings, and particularly so in neonatal intensive care.

The emotional intensity associated with such decision making is intense. This is from both the parental perspective, where there may be an expectation and hope that their child will survive at all costs. Such hope and expectation is linked to the strong parental love parents show towards their children⁴. Paediatricians may also feel a sense of failure in their duty of care to the patient and family when the child can no longer be cured and death becomes imminent. This can influence their decisions associated with withholding and withdrawing life-sustaining measures on occasions.

While the subject of sick and dying children is difficult and vastly uncomfortable for a society with increasing dependence on "the cure", there are a number of broad tenets, or principles, that clinicians should bear in mind when required to make difficult decisions in this area. It is now widely accepted in medicine, bioethics and the law that competent adults have the right to refuse medical treatment, even if that medical treatment would save their life. Second, doctors and health providers are under no obligation to offer

⁴ Gillis J, Rennick J. Affirming parental love in the pediatric intensive care unit. *Pediatr Crit Care Med*. 2006; 7(2):165-8.

therapy they judge to be medically futile (burdens and harms outweighing any benefits of proposed treatment).⁵ Third, Gillick-competent⁶ children and young people can consent to medical treatment but may be unable to refuse medical treatment if that treatment is determined to be in their best interests. Further discussion of the concept of best interests is contained in both Legal Considerations [Best Interests] and Ethics Considerations [The Best Interests of the Child].

Use of the word “child”

In the interests of brevity, this guideline uses the terms *child*, *children* and *young people* very generally, and sometimes interchangeably, to cover the biological age spectrum from birth through late teenage years. Where it is relevant, a specific biological age group will be identified. In the context of guidance for end-of-life decision-making, chronological age may be less important than an understanding of a child’s physical, cognitive, emotional, and spiritual development and the medical, social, and other support appropriate to different stages of development. Definitions of the periods of childhood vary somewhat and reflect a mix of biological and social considerations. From the literature on cognitive and biological development, it seems there have been challenges reaching a consensus on precise “cut-offs” for specific age groupings.⁷ The following represent the broad categories of biological age groupings for those under the age of 18 years:

Neonate: from birth through 4 weeks of age (under 28 days)

Infant: from 4 weeks of age through the end of the first year of life

Toddler: from 12 months to 3 years of age

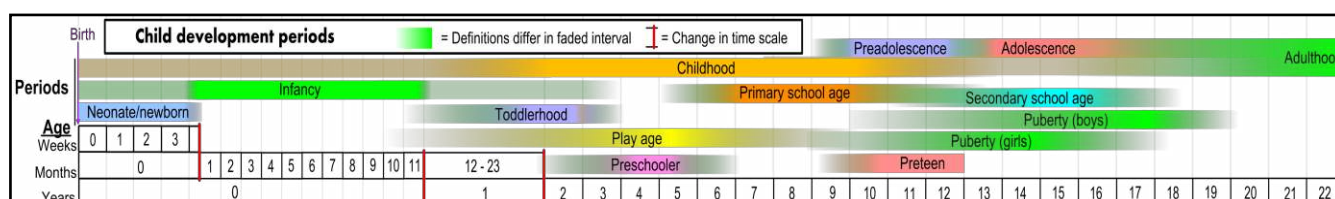
Preschool child: from ages 2 or 3 through to 4 or 5 years of age

Middle childhood: from age 5 through to 10 years of age

Pre- and/or early adolescents: from ages 10 through to 14 years of age

Adolescent: from age 13 through 17 or 19 years of age

Middle and late adolescent: from age 15 through 19



While aspects of child development are not the subject of these guidelines, a broad indication of the stages is required, particularly in discussions about children contributing

⁵ It should be acknowledged that the term “futile” or “futility” does carry with it some debate and controversy. There is significant disagreement about how futility is assessed, who defines and how it can be objectively applied to each situation. The problem in definition and concept of futility aside, the term is widely understood and in common usage across bioethical and legal spheres and is discussed separately in this guideline (See Ethical Considerations – Part 2 Ethical Considerations What is Futility).

⁶ Gillick-competent patients are generally adolescents under the age of 18 years who are considered to have sufficient maturity and cognitive development to consent to health care and contribute to health care decisions on their own behalf. The term is derived from a court case in the UK: *Gillick v West Norfolk and Wisbech Area Health Authority* [1985] 3 All ER 402 (HL). The case does not specify the age at which a child is regarded as competent, as this is unique for every circumstance.

⁷ Kail RE (2006), *Children and Their Development* (4 ed.), Prentice Hall: NY.

to decisions about their health care. The diagram above represents an approximate outline of developmental periods.⁸

Without taking a position in the moral and legal debate over what constitutes personhood, the guidelines also considers prenatal diagnosis of a life-threatening congenital condition. Some national and international guidance uses the term ‘extreme preterm’⁹ to cover the developmental characteristics of these infants. The Nuffield Council on Bioethics produced guidance in relation to resuscitation attempts for these infants; however it must be pointed out that this continues to be the subject of considerable debate and remains exceptionally controversial. Further detail will be provided in Clinical Considerations [Section: Infants with a correctable defect or extreme prematurity].

At 18, it is recognised that a person who has capacity may make his or her own decisions about matters such as health care and advance health directives. For those under the age of 18 years, while all may contribute to their health care decisions to the extent this is possible, only those considered competent may consent to medical treatment proposed to be provided. When a child is considered competent to consent to decisions about health care matters, they are often referred to as “Gillick-competent” [further discussion in Legal Considerations – Children with Capacity].

Context for decision-making about withholding and withdrawing life-sustaining measures

Paediatric health care providers who work in acute care settings today are increasingly called upon to care for infants or children undergoing highly complex treatment for a life-threatening illness. Although advances in science, medicine, and nursing have been effective in saving or prolonging the lives of many children, some children die amidst intensive treatment. Unfortunately many patients, including children, die in intensive care following an active decision to discontinue treatment, or following a decision not to commence life-sustaining measures. A review of published national and international literature suggests that there is considerable variation around the world in regard to the proportion of children managed by withdrawal or limitation of life-sustaining measures, and the level to which parents are involved in the decision-making. In studies from North America and Europe, 30-65% of deaths in paediatric ICUs followed with withholding and withdrawing of life-sustaining measures. In contrast, in South America only 18-32% of deaths followed withholding or withdrawing of life-sustaining measures with over half the deaths occurring after failed CPR attempts.¹⁰

A more paternalistic approach in those communities to such decisions could be reflective of different attitudes and clinical behaviour with regard to the dying; or it may be for more pragmatic reasons, such as under-funded paediatric units not capable of accepting infants and children with a poor prognosis. Studies from Brazil and Argentina report that family involvement in decision-making is as low as 9% in some hospitals.¹¹ In contrast,

⁸ http://commons.wikimedia.org/wiki/File:Child_development_stages.svg

⁹ Johanson M, Odesjö H, Jacobsson B, Sandberg K, Wennerholm UB., Extreme preterm birth: onset of delivery and its effect on infant survival and morbidity. *Obstet Gynecol.* 2008 Jan;111(1):42-50.

¹⁰ Devictor DJ, Nguyen DT. Forgoing life-sustaining treatments in children: a comparison between northern and southern European pediatric intensive care units. *Pediatr. Crit. Care Med.* 2004; 5: 211–15; Zawistowski CA, DeVita MA. A descriptive study of children dying in the pediatric intensive care unit after withdrawal of life-sustaining treatment. *Pediatr. Crit. Care Med.* 2004; 5: 216–23; Kipper DJ, Piva JP, Garcia PCR *et al.* Evolutions of the medical practices and modes of death on pediatric intensive care units in southern Brazil. *Pediatr. Crit. Care Med.* 2005; 6: 258–63; Lago PM, Piva J, Kipper D *et al.* Life Support limitation at three pediatric intensive care units in southern Brazil. *J. Pediatr. (Rio J.)* 2005; 81: 111–17.

¹¹ Athabe M, Cardigni G, Vassallo JC *et al.* Dying in the intensive care unit: collaborative multi-centre study about forgoing life-sustaining treatment in Argentine pediatric intensive care units. *Pediatr. Crit. Care Med.* 2003; 4: 164–9; Kipper DJ, Piva JP, Garcia PCR *et al.* Evolutions of the medical practices and modes of

other studies from North America, UK and Australia had significant parental involvement and consultation in decision-making regarding withholding and withdrawing of life-sustaining medical treatment from children.

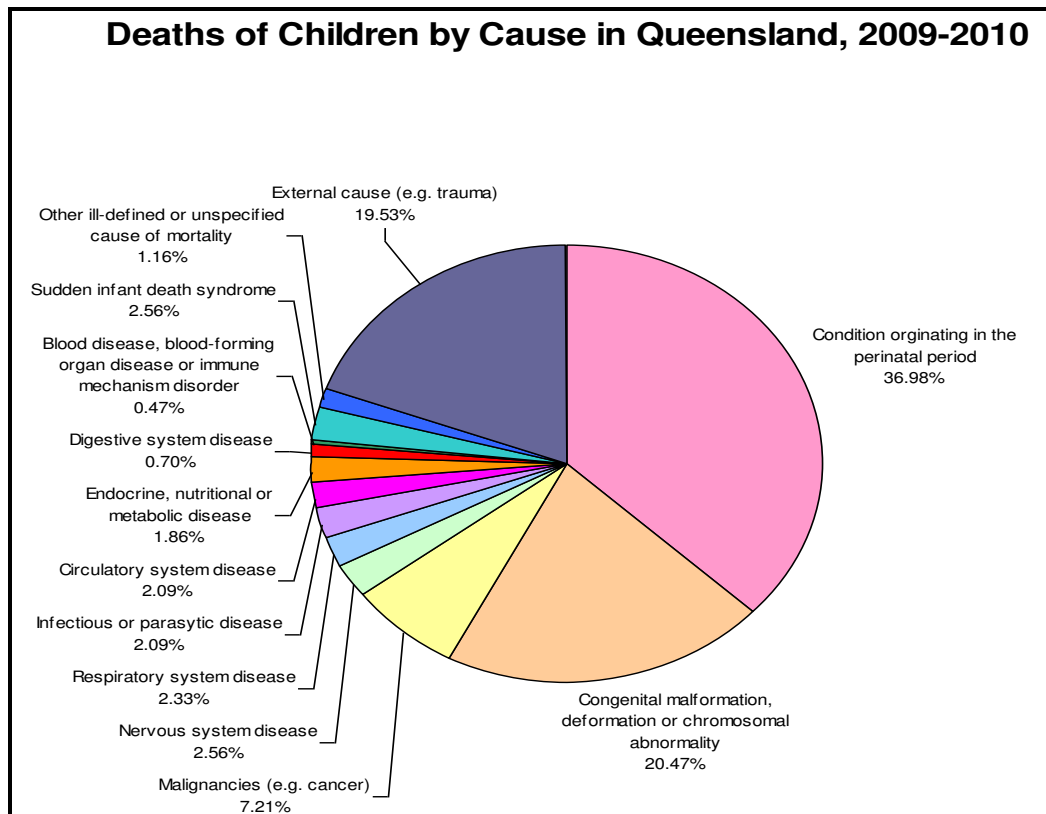
What does this tell us, and how does this make a difference to the way paediatric care should be delivered to dying patients under the age of 18 years? It provides a backdrop against which benchmarks for clinical practice can be established, as these issues are not clearly delineated. For many of the decisions around withholding and withdrawing life-sustaining medical treatment, it is not exclusively from the science of medicine that we will find the answers. Advances in biology, science and medical technology have dramatically changed the medical landscape and our place in it. Medicine now has the capacity to prolong life beyond the point at which it may be perceived to have any benefit. So often there is very little question that we *can* do it; that we are capable of sustaining life long beyond the point at which there is any potential viability of recovery for the patient. But *should* we do this at the expense of an individual's best interests, dignity and wellbeing? It is addressing the premise behind these questions that the discussion must turn to ethical (and legal) arguments; forcing us to examine the difficult questions regarding human identity, personhood, rights and responsibilities with regard to access to medical care, the goals of health care, what life means, and the very manner of death and dying itself. [Further discussion of this concept is in Ethical Considerations – Section Exploring Ethical Themes and Moral Questions].

In developed nations, it is estimated that, each year, 10 per 10 000 children aged 0–19 years will require palliative care. This means that, at any one time, up to 5300 Australian children in this age group will have a life-limiting condition, about half of whom may need “active” palliative care. Some authors have suggested this figure may be even higher.¹² In Queensland, the following statistics on deceased children (under the age of 18 years) are sourced from the *Annual Report: Deaths of Children and Young People*.¹³

death on pediatric intensive care units in southern Brazil. *Pediatr. Crit. Care Med.* 2005; 6: 258–63; Lago PM, Piva J, Kipper D *et al.* Life Support limitation at three pediatric intensive care units in southern Brazil. *J. Pediatr. (Rio J.)* 2005; 81: 111–17.

¹² Lenton S, Stallard P, Lewis M, Mastroiannopoulou K. Prevalence and morbidity associated with non-malignant, life-threatening conditions in childhood. *Child Care Health Dev* 2001; 27: 389-398.

¹³ Prepared by the Commission for Children and Young People and Child Guardian



The number of children (<18) who died in Queensland in the year 2009/10 is 430 – 46.3 deaths per 100,000 children generally or 33.1 deaths per 100,000 excluding trauma.¹⁴ This represents approximately 1.6% of all deaths occurring in Queensland.¹⁵ While statistics are not readily available on the place of death, it is assumed that the vast majority of these children died in a hospital setting. From the graph above, it can be seen that children who die from life-limiting conditions are a very diverse population: almost 37% of deaths are attributed to conditions originating in the perinatal period, just over 20% have conditions relating to congenital malformation, trauma victims account for almost 20% of deaths, less than 10 per cent have a malignancy, and the remainder has a range of often rare conditions, including other congenital abnormalities and neurodegenerative disorders. In such a diverse population there are a variety of illness trajectories:¹⁶

- potentially curable conditions for which curative treatment proves unsuccessful (e.g. malignancy);
- conditions in which intensive therapy prolongs and enhances life before a premature death (e.g. cystic fibrosis);
- progressive conditions for which no curative or disease altering therapy is available (e.g. neuro-degenerative disorders); or
- non-progressive conditions in which the child is highly likely to die before adulthood as a result of complications such as protracted seizures or respiratory failure (e.g. severe cerebral palsy).

¹⁴ Commission for Children and Young People and Child Guardian, 2010. Queensland Government. *Annual Report: Deaths of Children and Young People*

¹⁵ A total of 27335 people died in Queensland in the year 2008. (ABS – Mortality statistics).

¹⁶ Hynson, J. Gillis, J. et al. (2003). The dying child: how is care different? *MJA* 2003; S20-S22

Toward principles for withholding and withdrawing life-sustaining medical treatment for those under the age of 18

Increasingly, death occurs not as a consequence of the 'natural' progression of disease, but because of a decision to discontinue medical treatment. While such decisions are profoundly difficult, particularly if we are close to the child and his or her family, they are particularly complex, both morally and ethically, in relation to the care of neonates and younger children. Some of this complexity can be attributed to the considerable diagnostic and prognostic uncertainty, and the difficulties of assessing functional abilities in children. Beyond that, a dying child tragically represents the end of hopes, dreams and aspirations the parents held that the child will see adulthood. End-of-life decision-making challenges are also amplified for patients under 18 years because they must rely on the test of 'best interests' as judged by others. While this is in almost all instances, the child's parent/s, each case, each family presents a new and unique opportunity for the health care team to provide treatment and care to ensure that to the best extent possible, the child's interests are upheld and protected.

The evidence of the benefits, burdens and risks of these treatments is not always clear cut, and there may be uncertainty about the clinical effect of a treatment for a child, or about the particular benefits, burdens and risks the child might experience. In some circumstances these treatments may only prolong the dying process or cause the child and his or her parent/s unnecessary distress. Given the uncertainties, the paediatrician or medical officer with support from other members of the health care team may need reassurance about what is ethically and legally permissible, especially when deciding whether to withhold or withdraw a potentially life-prolonging treatment from a child they have been caring for.

The following guiding principles for caring for dying children are based on those sourced from the Royal Australasian College of Physicians,¹⁷ US Institute of Medicine in 2003,¹⁸ the Nuffield Council on Bioethics¹⁹ and the UK End of Life guidance, and serve as a good launching point for the clinical, legal and ethical considerations discussed throughout these guidelines:

¹⁷ Royal Australasian College of Physicians (Paediatrics and Child Health Division). (2008). Decision-making at the end of life in infants, children and adolescents. RACP, Sydney: NSW.

¹⁸ Institute of Medicine, USA. (2003). *When children die: Improving palliative and end-of-life care for children and their families*. The National Academies Press. Washington DC. pp. 29 – 33.

¹⁹ Nuffield Council on Bioethics. (2006). Critical care decisions in fetal and neonatal medicine: ethical issues. <http://www.nuffieldbioethics.org/sites/default/files/CCD%20web%20version%2022%20June%2007%20%28updated%29.pdf>

Guiding principles to support ethical practice in withholding and withdrawing life-sustaining measures for neonates, children and adolescents

1. There is no significant ethical difference between withdrawing (stopping) and withholding (not providing) treatments, given the same ethical objective.
2. Optimal ethical decision-making concerning children requires open and timely communication between members of the health care team and the child and family, respecting their values and beliefs and the fundamental principles of ethics and human rights.
3. Parents may ethically and legally decide on behalf of children who are unable, for whatever reason, to express preferences, unless they are clearly acting against the child's best interest or are unable, unwilling or persistently unavailable to make decisions on behalf of their child.
4. The wishes of a child who has obtained sufficient understanding and experience in the evaluation of treatment options should be given substantial consideration in the decision making process.
5. The antecedent wishes and preferences of the child, if known, should also carry considerable weight given that conditions at the time for action match those envisaged in advance.
6. In general, resolution of disagreement should be by discussion, consultation and consensus.
7. The duty of care is not an absolute duty to preserve life by all means. There is no obligation to provide life sustaining treatment if:
 - its use is inconsistent with the aims and objectives of an appropriate treatment plan
 - the benefits of that treatment no longer outweigh the burden to the patient.
8. It is ethical to withdraw life sustaining treatment if refused by a competent child; or from children who are unable to express wishes and preference when health care team and parent/carers agree that such treatment is not in the child's best interests.
9. A redirection of management from life sustaining treatment to palliation represents a change in beneficial aims and objectives and does not constitute a withdrawal of care.
10. The range of life sustaining treatments is wide and will vary with the individual circumstances of the patient. It is never permissible to withdraw procedures designed to alleviate pain or promote comfort.
11. There is a distinction to be drawn between treatment of the dying patient and euthanasia. When a dying patient is receiving palliative care, the underlying cause of death is the disease process. In euthanasia, the intended action is to cause death.
12. It follows that use of medication and other treatments which may incidentally hasten death may be justified if their primary aim is to relieve suffering. The practice of euthanasia in Australia is prohibited, and this is reflected in all Queensland Health documentation around end-of-life decision-making.
13. Legal intervention should be considered when disputes between the health care team, the child, parents and carers cannot be resolved by attempts to achieve consensus.

CLINICAL CONSIDERATIONS

Care for children necessarily differs from care for adults, reflecting children's developing physiological, psychological, and cognitive characteristics and their legal, ethical, and social status. These differences are reflected in the development of paediatric specialties in medicine and other health professions, the creation of specialised paediatric centres and other care settings, and the growth of educational programs and research dedicated to improving care for children. Professionals in the evolving fields of palliative and end-of-life care are meeting this challenge and applying their principles to children and considering how to train paediatric and palliative care specialists as well as others who regularly care for children and families facing medical problems that are likely to end in the child's death. The importance of such efforts is increasingly being recognised and adopted more routinely into good medical practice.

Many health care professionals provide excellent, sensitive palliative, end-of-life, and bereavement care to children and their families. Nonetheless, shortcomings in care can too frequently be found, some of which find their way into media articles and scholarly journals on the subject. Effective, compassionate, reliable palliative and end-of-life care has not usually been a priority for health care providers, managers, researchers, policymakers, or the general public.²⁰ Some of the more difficult issues in palliative and end-of-life care for children that are mentioned in this guidance are similar to those experienced by adults. For example, frightened and upset patients and families may receive confusing or misleading explanations of diagnosis, prognosis, and care options. They may likewise be required to make decisions at the "11th hour" and have very little opportunity to absorb shocking information, ask questions, and reflect on goals and decisions, even when no immediate crisis is driving decision-making.

Appropriate withholding and withdrawing of life-sustaining measures in children with advanced disease should result in these children dying with comfort and dignity in the presence of their families. There are also financial and resource allocation issues that need to be considered when care is provided to dying children which is felt to be futile or ineffective. There is some evidence to suggest that overall an effective palliative care program in a children's hospital will reduce hospitalisation costs due to a reduction in utilisation of expensive and ineffective treatments²¹. However, these benefits are likely to occur when a palliative approach is applied to a population of patients. There is emerging evidence that palliative care referrals do reduce the number of intensive care admissions and increase the number of patients dying at home or in hospices²².

However, there are a small number of patients receiving palliative care where a longer admission to hospital is required²³. Some argue that the economic or resource allocation principle should not overshadow good clinical care in conjunction with meeting the parent's requests when dealing with a single case at hand. Gillis argues that the number

²⁰ Institute of Medicine, (2003). Board on Health Sciences Policy. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. National Academies Press: Washington, D.C. p. 21

²¹ Gans D, Kominski GF, Roby DH et al. Better Outcomes, Lower Costs: Palliative Care Program Reduces Stress, Costs of care for Children With Life-threatening Conditions. UCLA Center for Health Policy Research and Children's Hospice and Palliative Care Coalition. August 2012.

²² Fraser L, Miller M, Draper ES et al. (2011). Place of death and palliative care following discharge from paediatric intensive care units. *Arch Dis Child*. 2011; 96(12):1195-8.

²³ Fraser L, Miller M, Aldridge J. Clinical and Demographic Predictors of Long Stays in Children with Non-Oncology Life Limiting Conditions. Oral presentation at 6th International Cardiff Conference on Paediatric Palliative Care, Cardiff, July 11 – 13, 2012.

of parents who request invasive resuscitation and management in paediatric intensive care units, against the advice of health professionals, is small²⁴. Further, the benefit to the parents and other family members to abiding by their wishes for a number of days outweighs the potential benefit to the parent for their remaining life and that the financial cost of this is relatively small within the overall health budget. This is a unique argument to paediatrics, partly due to the small number of children who die each year (500 children compared to 25 000 adults in Queensland) and is not as applicable to adult practice. Truog also argues that we must consider the welfare of parents who will remember the way decisions were made in relation to end of life care for the rest of their lives²⁵. This impact is much greater on the parent of the child than health professionals involved in the case in the subsequent years.

Diagnosis and prognostication

Unfortunately some children are born with rarely seen medical conditions, which create uncertainty in diagnosis, prognosis, and treatment planning. Even for common medical problems, children's general physiologic resiliency complicates predictions about survival and other outcomes. In situations laden with fear, anxiety, and desperation, this greater uncertainty complicates the health care team's and family's efforts to assess and weigh the potential harms and benefits of treatment options.²⁶ Also, those children with life-threatening medical conditions from rural and remote areas are not significant in number to build local experience and clinical expertise. This results in care for these children being located in centres away from their home. Travel required in such instances results in the child and family being removed from their usual sources of emotional and social support, disruptions to parents' employment, and strained family relationships and finances.

Overly optimistic estimates of prognosis are a common barrier to initiation of palliative care.²⁷ However, the introduction of palliative care does not mean that curative treatments, which seek to reverse the disease process, need to be terminated if they remain appropriate.²⁸ Although medical teams often worry that families "are not ready" to address these issues, evidence show that integration of palliative care does not lessen parents' hope.²⁹ In addition, prognostic information that clinicians considered upsetting does not lessen a parent's desire for this information, and is often considered important to decision making.³⁰

Clinical decisions to withhold or withdraw life-sustaining measures seek to avoid unwanted, excessively burdensome or insufficiently beneficial interventions for patients at the end of life. Discussions about withholding and withdrawing life-sustaining for measures should always be approached with sensitivity and with close attention to the clinical context and specific goals and desires of the individual for whom the measures are being considered. In the case of those patients under the age of 18 years, particular attention should be paid to the concept of the child's best interests.

²⁴ Gillis J (2008). We Want Everything Done. *Arch Dis Child*. 2008; 93(3):192-3.

²⁵ Truog R (2010). Is it always wrong to perform futile CPR? *NEJM*. 2010; 362 (6): 477- 479.

²⁶ *Ibid.*, p. 22.

²⁷ Davies B, Sehring SA, Partridge JC, et al. Barriers to palliative care for children: perceptions of pediatric health care providers. *Pediatrics* 2008; 121:282.

²⁸ American Academy of Pediatrics. Committee on Bioethics and Committee on Hospital Care. Palliative care for children. *Pediatrics* 2000; 106:351.

²⁹ Mack JW, Wolfe J, Cook EF, et al. Hope and prognostic disclosure. *J Clin Oncol* 2007; 25:5636

³⁰ Mack JW, Wolfe J, Grier HE, et al. Communication about prognosis between parents and physicians of children with cancer: parent preferences and the impact of prognostic information. *J Clin Oncol* 2006; 24:5265.

Good medical practice

The practice of medicine is complex and multifaceted, but the key objective is to serve the best interests of the patient. Medical officers are expected to base their practice of medicine on some fundamental principles including - integrity, truthfulness, fidelity, compassion, and confidentiality. Guidelines recently released by the Australian Medical Council on good medical practice also include the qualities of patient-centeredness, good communication and clinical judgement.³¹

Professional judgments are made by medical officers about how they practice medicine and apply these qualities. It is acknowledged that sometimes these judgements may conflict with the parent's wishes for end-of-life care for their child. Good medical practice also requires the child's wishes to be respected to the greatest practical extent, according to their level of cognitive development and maturity. There is significant case law supporting "Gillick-competent" children being responsible for consenting to their own health care, rather than their parents. [Further discussion of the legal aspects of consent requirements for children is in the Legal Considerations – Section Consent].

Good medical practice also involves establishing a relationship with the paediatric patient and his or her family to ensure the best interests of the young patient is upheld in all decision-making. In cases where the child has impaired capacity or their biological development does not allow for active communication, positive approaches must be made by the health care team to the parents of that child to ensure the parent/s become involved in decision-making on their child's behalf to the maximum extent possible. In discussing the range of options available, the medical officer responsible for care of the child should offer only treatments that are reasonably considered, in all the known circumstances, to be of potential benefit to that patient. Offering treatment that for clinical reasons would be potentially futile and could cause harm to the paediatric patient is considered cruel and inhumane and not conducive to a beneficial patient-clinician relationship. Initiating life-sustaining medical treatment in cases where there is no conceivable benefit to the child prolongs the inevitable event when the equally difficult decision will have to be made to withdraw that treatment.

Where doubt exists about the diagnosis or prognosis, advice should be sought from a paediatrician or other senior clinician with experience of that condition before making decisions about withholding or withdrawing active medical treatment. This should also be the case when the health care team has limited experience of the condition, particularly with comparatively rare disorders, or there are disparate views about treatment. For example, where a child is in a post-coma unresponsive state, advice will usually be sought from a clinician with expertise in the long-term consequences and management of brain injury or neurological conditions. Where the child is born extremely preterm, advice should be sought from a neonatologist should one not be present at the birth.

Where the paediatrician or medical officer responsible for a child's care has reasonable doubts about a treatment's potential benefit (or concerns the treatment could cause potential harm), treatment should be given for a trial period with a subsequent pre-arranged review. If, following the review, it is decided the treatment has failed or ceased to be of benefit to the patient, its withdrawal may be considered. An appropriate consent pathway must be followed if there are any changes to prognostic information following expert opinion.

³¹ Australian Medical Council. Australian Medical Council, *Good Medical Practice: A Code of Conduct for Medical officers in Australia*, July 2010.

Treatment should never be withheld merely on the grounds that it is easier to withhold treatment than to withdraw treatment which has been initiated.

A medical officer will be protected from criminal liability where they provide palliative care in good faith and with reasonable care and skill. The care must be reasonable having regard to the child's condition at the time and the individual circumstances and must be documented by the medical officer in charge of the child's care. This protection, however, does not permit euthanasia or assisted suicide. [For further discussion of protections for clinicians, see Legal Considerations].

Making sound clinical judgements

The starting point for reaching good decisions is careful consideration of the child's clinical situation. The medical officer must carry out a thorough assessment of the child's condition and consider the likely prognosis. It can be difficult to estimate when any patient is approaching the end of life, and a range of possibilities and uncertainties should be kept in mind when planning care.

The paediatrician or medical officer responsible for the care of the child should identify treatment options based on:

- up-to-date clinical evidence about effectiveness, side effects and other risks
- relevant clinical guidelines on the treatment and management of the child's condition, or of children with similar underlying risk factors, such as those published nationally and internationally.³²

Early consideration must be given to the child's palliative care needs, steps taken to manage any pain, other distressing physical or psychological symptoms that they may be experiencing, as well as keeping their nutrition and hydration status under review. Advice or second opinions must be sought from a colleague with relevant experience (who may be from another specialty, such as palliative care, or another discipline, such as nursing) if:

- (a) the health care team has limited experience of the condition
- (b) there is uncertainty about how to manage the child's symptoms effectively
- (c) there are doubts about the range of options, or the benefits, burdens and risks of a particular option for the child
- (d) there is a serious difference of opinion between the health care team and the parents of the patient or within the health care team about the preferred option for a child's treatment and care
- (e) it is decided that clinically assisted nutrition or hydration should be withdrawn or withheld.

Addressing uncertainty

If there is a reasonable degree of uncertainty about whether a particular treatment will provide overall benefit for the child, the treatment should be started in order to allow a clearer assessment to be made. In these cases, this must be explained clearly to the parents and the health care team that the treatment will be monitored and reviewed, and may be withdrawn at a later stage if it proves ineffective or too burdensome for the patient in relation to the benefits. The paediatrician or medical officer responsible for the care of

³² General Medical Council UK. (2010). *Treatment and care towards the end of life: good practice in decision-making*. [http://www.gmc-uk.org/static/documents/content/End_of_life.pdf]. American Academy of Pediatrics. (2000). *Palliative Care for Children*. Committee on Bioethics and Committee on Hospital Care. [<http://aappolicy.aappublications.org/cgi/reprint/pediatrics;106/2/351.pdf>]

the child should explain the basis on which the decision will be made about whether the treatment will continue or be withdrawn.

However, it is not necessary to have absolute certainty in order to make a decision. As in so many areas of medicine, absolute certainty may not exist in settings where major decisions need to be made and judgement will be required to determine the appropriate way forward, particularly in emergency situations. There may be times when there is doubt about the potential benefits of a particular intervention. In such circumstances, it may be reasonable to conduct the treatment over a well-defined and pre-negotiated trial period. If, at the end of that time, no benefit is demonstrated or the burdens of treatment outweigh the benefits, consideration should be given to withdrawing the treatment.

Emergencies: with limited information about the child

Medical treatment can be provided to a child or young person with their consent if they have capacity to make the decision, or with the consent of the child's parent/s, guardian/s or the court. Emergency treatment can be provided without consent to save the life of, or prevent serious deterioration in the health of a child or young person. More detailed guidance on the different decision-making authority of people with parental responsibility is in Legal Considerations [Section Consent].

A life-threatening emergency can arise where the health care team has no previous knowledge of, or inadequate information about, the child's medical history or wishes regarding treatment, and where any delay might prejudice the outcome. In these circumstances it may not be possible to obtain all relevant information or hold any consultations before making a decision. In such cases, clinical judgement must be exercised at the time the decision is required.

In deciding whether to withhold or withdraw a particular treatment, the views of the parent/s or person/s with parental authority that are recorded in the medical chart or otherwise drawn to your attention by other members of the health care team must be respected. If there is no parent or person with parental authority available to discuss the best interests of the clinical approach, a considered clinical judgement about the child's best interests based on the standards of good medical practice must be made. Where there is a reasonable degree of uncertainty about the appropriateness of any treatment, a second opinion should be obtained, as discussed above. Clear explanation of the reasons for the clinical decisions must be given to the child's parents, if they are available, and to the child should they recover sufficiently to understand.

Life-sustaining measures

For a child with life-threatening illness, invasive and life-sustaining measures, such as CPR, assisted ventilation and nutrition may be available even at the end of life. Prior to a life-threatening event, it is important to consider whether such interventions should be performed. Early discussion allows children and parents to make decisions that fit with their values and goals of care.³³ This assessment should consider whether any of the proposed interventions (e.g. intubation, chest compressions, defibrillation) will help reverse the primary problem.

While the principles behind decision-making about life-sustaining measures are the same for all patients, the law operates differently depending upon whether the patient is aged

³³ Mack JW, Wolfe J. Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis. *Curr Opin Pediatr* 2006; 18:10.

18 years or over. Queensland's legislation³⁴ provides a definition of life-sustaining measures for the purposes of decision-making for adult patients with impaired capacity. The particular piece of legislation, while it does not apply to children offers a starting point in guiding our health care professionals who are required to make such decisions for those patients under the age of 18 years. Queensland's legislation⁴ defines life-sustaining measures as follows:

- (1) A life-sustaining measure is health care intended to sustain or prolong life and that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation.
- (2) Without limiting subsection (1), each of the following is a life-sustaining measure:
 - (a) cardiopulmonary resuscitation;
 - (b) assisted ventilation;
 - (c) artificial nutrition and hydration.
- (3) A blood transfusion is not a life-sustaining measure.

From this definition, we can see that life-sustaining measures are interventions required to immediately save the life and health of an individual, and the logic of this does include children. However, it should be noted that in the case of blood transfusions, parental consent is not required if the transfusion is to be provided in the best interests of the child. Further discussion about blood transfusions is contained in both Legal Considerations – Section [Consent] and Clinical Considerations – Section [Blood Transfusions].

As with adult patients, the decision to provide or not provide life-sustaining measures, and when, can be controversial and emotive in both the literature and in clinical practice. Notwithstanding the issues around consent, some of the more difficult and challenging circumstances in decision-making about life-sustaining measures surround the use of clinically-assisted hydration and nutrition, and mechanical ventilation. However, this is the case for all dying patients. Irrespective of the clinical decisions about specific "life-sustaining" measures, it is the policy of Queensland Health that where there is doubt or uncertainty about resuscitation measures, or indeed, where a second opinion is required, that the decision must favour life. That is, resuscitation attempts must be made while the child is kept as free from pain and distress as clinically possible. The health care team, guided by the paediatrician or senior medical officer, should also ensure that even if a consensus is reached about not continuing with active treatment because there will be no benefits in doing so, care for the dying always involves the provision of comfort measures; comfort care is never futile, indeed it is obligatory.

Is withholding life-sustaining treatment different to withdrawing it?

Ethically and legally, it is said that there is no difference between withdrawal and withholding of an intervention.³⁵ Therefore, based on this logic, any intervention which may be ethically withheld may also be ethically withdrawn. There is a plethora of ethical and legal argument that whirls around this premise, involving concepts such as "acts" and "omissions" on the legal side, and notions of equivalence and double-effect on the side of ethics. Why this distinction is important in the eyes of some is the fear that therapies may not be initiated for fear of not being able to justify their withdrawal later on. Put another

³⁴ Powers of Attorney Act 1998 (Qld) & Guardianship and Administration Act 2000, sch. 2, s. 5A

³⁵ General Medical Council, UK. *Treatment and care towards the end of life: good practice in decision making*. [Accessed 31 March 2011] http://www.gmc-uk.org/guidance/ethical_guidance/6858.asp

way: the problem about making a distinction between withdrawing and withholding treatment is that this can lead people to decide not to start treatment that might be effective because they are worried that they will not be able to stop it. Thus, it may be reasonable in some circumstances to begin treatment with a view to ceasing it later on if no benefits are seen. While some believe the moral equivalence reasoning makes decision-making in this area seem more straight-forward, others are not so certain.³⁶

Therefore, it is worth pursuing a line of inquiry that questions the basis of this premise, but at the same time preserves the dictum that there is no ethical difference between the two. In Queensland, the term “withholding and withdrawing” as it relates to life-sustaining medical treatment appears in two pieces of legislation.³⁷ While both Acts combines “withholding and withdrawing” medical treatment as a collective term, arguably, the two operate under quite different clinical decision-making paradigms. The clinical decision-making for both circumstances (that is, to withhold and/or withdraw) is affected by:

- (i) The level of clinical uncertainty; and
- (ii) The timeframe available for decision-making.

The lines between the two decisions may converge ethically, but they diverge clinically. The decision to *withhold* medical treatment is largely prospective: that is, the decision is based on whether or not to commence treatment for an event/s yet to take place. This may involve a dimension of uncertainty, because there could be considerable variables and unknowns about the future clinical state of the patient, for example, when and if the patient will suffer a cardiac arrest, necessitating CPR.

The decision to *withdraw* a life-sustaining measure implies that a level of acceptance about the benefits of continuing the measures has been reached, both by the clinicians involved and the family of the patient. The decision signifies that a stage has been reached where the evidence points to the fact that the patient undeniably and irrefutably is receiving no benefit from the interventions proposed to be withdrawn. In such cases, arguably, the consent processes for withdrawing medical treatment may be less onerous than for withholding medical treatment, most likely because the patient’s condition has stabilised to the extent that no further improvement is expected. In these cases, families may have had an opportunity to arrive at the decision that nothing further can be done for their loved one.

In some cases, consent may not need to be obtained to *commence or continue* life-sustaining medical treatment (for example, under urgent health care, duty of care and “necessaries of life” provisions), but consent should be obtained to withhold or withdraw the measures. This may be the source of some confusion for families. The explanation is that decisions to withdraw medical treatment almost always occur in non-urgent clinical situations, where there is time to discuss all of the issues with the patient’s family and obtain their consent.

Decisions of this nature are always difficult and complex, and need to involve close consultation and effective communication with the health care team, the patient and those

³⁶ Sulmasy DP and Sugarman J. (1994). Are withholding and withdrawing therapy always morally equivalent? *Journal of Medical Ethics* 1994; 20: 218-222. Wilkinson, D. (2010). University of Oxford. A costly separation between withdrawing and withholding treatment. *Practical Ethics*. Published June 17, 2010.

[<http://blog.practicaethics.ox.ac.uk/2010/06/a-costly-separation-between-withdrawing-and-withholding-treatment/>]. Meiltoor G & Nilstun I. The difference between withholding and withdrawing life-sustaining treatment. *Intensive Care Med* (1997) 23:1264-1267. Levin PD & Sprung CL. Withdrawing and withholding life-sustaining therapies are not the same. *Critical Care*. June 2005. 9: 3

³⁷ *Guardianship and Administration Act 2000* and *Powers of Attorney Act 1998*

close to the patient. How well a paediatrician or medical officer can broach this sensitive topic with patient and family correlates to how well the patient and family understand and accept this information and trust that the health care team has the best interests of their loved one at the forefront of their treatment plan and goals.

Finally, there is one further practical difference between withdrawing and withholding medical treatment that is highly controversial and does not appear in most descriptions of the debate. Decisions about admissions to intensive care are often influenced by resources. Unfortunately there are not enough intensive care beds available to treat every patient who suffers acute organ failure. While there is a general tenet in health care that resource considerations should never play a role in decisions to cease life-support, the reality is that doctors have to allocate resources appropriately by prioritising intensive care beds to those who will benefit from them the most. Continuing with this logic, since resources play a role in treatment starting decisions but never in treatment stopping decisions, this, arguably provides another good reason for distinguishing between the two. Distributive justice demands that difficult decisions must be made about limited resources. But, if such decisions can only be made prior to admission to intensive care, and not once people are through the door, then it follows that these decisions will be treated differently.

Resuscitation planning

Resuscitation planning in these guidelines refers to advance discussions and decisions regarding actions to be taken for a patient in the event of a cardiac and/or respiratory arrest. In all instances this will involve consideration of CPR. However, other life-sustaining measures may also be appropriate, according to good medical practice. Comfort care and palliative support must always be initiated if the decision is to withhold or withdraw active medical treatment. Planning resuscitation for a child depends on the extent to which death is regarded as an unavoidable and impending consequence of the child's underlying illness. The paediatrician or medical officer responsible for the care of the patient has an important role in those responsible for decision-making to make appropriate plans for the child's future care in a sensitive but realistic manner, making clear if resuscitation methods could be successful.

It is Queensland Health's policy that the requirement for CPR is considered an emergency in all cases. However, as with some clinical aspects of end-of-life care, the requirement for CPR can be reasonably predicted. Therefore consent will not be required if the decision needs to be made immediately. Emergencies arise when there is no time to make a proper assessment of the child's condition and the likely outcome of CPR; when no previous decision about whether to provide or not provide CPR is in place; and when it is not possible to find out the parent's or the child's views. In these circumstances, CPR should be attempted, unless it is certain there is sufficient information about the child to judge that it will not be clinically successful, nor in their best interests.

Discussions about circumstances in which CPR should not be attempted can be difficult and distressing for all concerned, particularly in the case of patients under the age of 18 years. It is important to offer "Gillick-competent" young persons an opportunity to discuss their future care and the circumstances in which CPR should or should not be attempted. The discussion of CPR in this context should be aimed at the young person's level of maturity and cognitive development. Failing to give such a young person the opportunity to be involved in reaching a decision could potentially cause more distress at a later stage. Parent/s or those with parental authority must be involved in these discussions.

Information should not be withheld simply because conveying it is difficult or uncomfortable for you or the health care team.

In some cases, parents may resist any discussion of CPR to be held with their child. These situations must be dealt with on a case-by-case basis, adhering to the standards of good medical practice, and always upholding the best interests of the child involved. The maturing autonomous child may well be capable of understanding the situation and participating in their own decisions about end-of-life care. Parents will be the best guide to knowing whether their child will cope with such a discussion. Some children, even those who may be “Gillick-competent,” may not wish to be given the details about CPR and what this might mean for their future care. The wishes of these children must be respected. Decision-making in these circumstances becomes the responsibility of their parent/s or person/s with parental authority.

Nonetheless, there is still legal uncertainty about the status of medical treatment refusals made by patients under the age of 18 years.³⁸ If the refusal of CPR is not in the best interests of the child, the parent/s or person/s with parental authority will be responsible for consenting on the child’s behalf. Where the parent/s refuse to consent on their child’s behalf, and the paediatrician or medical officer responsible for care of the child sincerely believes it is in the best interests of the child to have CPR, a formal application for consent *to provide CPR* will be needed from the Court. Further information and guidance about treatment refusals by patients under the age of 18 years is contained in the Legal Considerations – Section [Treatment Refusals].

The Paediatric Acute Resuscitation Plan (PARP)

Queensland Health has developed a Paediatric Acute Resuscitation Plan form (PARP) to formalise the decision-making documentation process for resuscitation of patients considered “at risk” of cardiac and/or respiratory arrest. NFR Orders have been replaced by the PARP form, which has been developed in consultation with clinicians.

The PARP form provides for consistent documentation of clinical recommendations to withhold or withdraw life-sustaining measures, including CPR and assisted ventilation. In conjunction with these guidelines, the PARP form is also intended to prompt discussion with parents of acutely ill children, or the children themselves should they be competent, about resuscitation planning in the event of an acute event, such as cardiac or respiratory arrest. A PARP can be valid for the current admission, until a specified future date or for the current and subsequent admissions.

In anticipation of the patient’s deteriorating condition, discussions about end-of-life decision-making are best initiated as soon as practicable. This will identify any unmet needs and preferences and give a clear decision path for other members of the health care team in the case of an acute event. Once a decision is made, the paediatrician or medical officer responsible for care of the child should record all details of the discussion about CPR held with the parents and the child (where applicable) on a PARP form. The decision/s should be appropriately communicated to all those involved in providing care to the patient. The PARP should be reviewed regularly to ensure it remains current and in the child’s best interests.

If a clinical decision is made *not* to provide CPR and there has been no discussion with the parents because they indicated a wish to avoid it, or because it was the considered

³⁸ White, McDonald and Willmott (2010). Health Law in Australia. p. 152

view of the doctor-in-charge that discussion with the parents was not appropriate, this should be noted in the medical record and also on the child's PARP.

It must be made clear to the parents of the child, to the child where this is appropriate, and to members of the health care team that not providing CPR does not mean that other measures will be limited or withheld. Other treatment and care will be provided if it is clinically appropriate and of overall benefit to the child, as negotiated with the parents and with the child if they are competent to make health care decisions.

A decision not to provide CPR should not override clinical judgement, for example if the child experiences cardiac or respiratory arrest from a reversible cause, such as the induction of anaesthesia during a planned procedure, or if the circumstances of the arrest are not those envisaged when the decision was made.

Cardiopulmonary resuscitation (CPR)

Risks, benefits and burdens

CPR, if attempted promptly in appropriate situations, may be effective in restarting the heart and lungs of some patients. Generally, however, CPR has a very low success rate and the burdens and risks of CPR include harmful side effects such as rib fracture and damage to internal organs; adverse clinical outcomes such as hypoxic brain damage; and other consequences for the patient such as increased physical disability. If the use of CPR is not successful in restarting the heart or breathing, and in restoring circulation, it may mean that the child dies in an undignified and traumatic manner. CPR also carries some risk of complications and harmful side effects, and if used inappropriately it may do more harm than good by prolonging the dying process and the pain or suffering of a seriously ill child, in a manner which could be seen as degrading and undignified. For example, if a child is at the end-stage of an incurable illness and death is imminent, attempts to resuscitate them are likely to be futile and not in their best interests.

Where a child is already seriously ill with a foreseeable risk of cardiopulmonary arrest, or is in poor general health and nearing the end of their life, decisions about whether to attempt CPR in particular circumstances ideally should be made in advance as part of the care plan for the child. In all cases, the proposed advance care plan should be discussed with the child's parent/s or person/s with parental authority to determine whether the level of burden or risk outweighs the likely benefits from successful CPR. This discussion would be central in deciding whether CPR should be attempted. In almost all circumstances, parent/s or person/s with parental authority will be responsible for providing consent about CPR decisions for their child.

Reaching the decision

Sometimes parents may request CPR for their child despite there being only a small chance of success, and even where the risk of distressing clinical and other outcomes outweighs any benefit. If the paediatrician or medical officer responsible for the care of the child considers that CPR would not be clinically appropriate, this should be communicated to the parents (and the child, where appropriate). Accurate information about the nature of possible CPR interventions and, for example, the length of survival and level of recovery that they might realistically expect if they were successfully resuscitated should also be discussed. The reasons for their request should be further explored and efforts made to reach agreement on the decision. When the benefits, burdens and risks are finely balanced, the child's best interests will usually be the deciding factor.

If, after discussing these matters with the parents, the paediatrician or medical officer responsible for the care of the child believes that CPR would not be clinically appropriate, there is no legal or ethical obligation to attempt it in the circumstances discussed. The reasons and any other options that may be available must be sensitively communicated to the parents (and the child, where appropriate), including seeking a second opinion.

While the final decision about the clinical merits of attempting resuscitation rests with the paediatrician or senior medical officer in charge of the child's care, good consistent communication between the health care team, the child and his or her parents is the key to ensuring that the child's rights are respected, the parent's are appropriately informed, and misunderstanding and unrealistic expectations are minimised.

Resuscitation planning is intended for those children who are considered in all reasonable circumstances to be at risk of cardiac and/or respiratory arrest in the foreseeable future. Resuscitation planning will be carried out with the parents (or person/s with parental authority) of the child. Discussing resuscitation planning with parents of children who are not acutely ill, particularly when not initiated by the parents, is likely to be inappropriate, and could be misinterpreted. However, for some of these children, often those with serious, chronic and ultimately fatal conditions, cardiac and/or respiratory arrest is an anticipated consequence of their illness. While this may be foreseen, the timing of an acute event is less predictable, and so resuscitation planning for appropriate response is desirable.

Clinically-assisted ventilation

Risks, benefits and burdens

The term clinically-assisted ventilation is recommended to replace artificial or mechanical ventilation, as is proposed in the *End of Life Guidelines* developed by the General Medical Council in the UK.³⁹ Clinically-assisted ventilation refers to the use of life-support technology to perform the work of breathing for patients who are unable to do so on their own. One of the most common reasons for ICU admission is the need for clinically-assisted ventilation. Patients most commonly require ventilation for respiratory failure or impending respiratory failure. Respiratory failure occurs during conditions of inadequate gas exchange of oxygen and/or carbon dioxide. This failure of adequate oxygenation or ventilation can occur as a result of lung disease, cardiac dysfunction, neurologic abnormalities, multi-organ system dysfunction/failure, and/or secondary to the effects of surgery or cardiopulmonary bypass. Primary lung injury can occur from a multitude of causes, including pneumonia, inhalation injury, chest trauma, near-drowning, haemorrhage, and aspiration. The overall goals of clinically-assisted ventilation are to optimise gas exchange, patient work of breathing, and patient comfort while minimising ventilator-induced lung injury.

Clinically-assisted ventilation has substantially improved outcomes of children suffering respiratory failure, by maintaining adequate oxygenation and ventilation until the underlying pathologic process resolves. It must also be recognised that clinically-assisted ventilation is supportive (not therapeutic) and positive-pressure mechanical ventilation

³⁹ 'Artificial nutrition and hydration' is the phrase sometimes used in health care settings. However, the GMC believes that 'clinically-assisted' is a more accurate description of the use of mechanical ventilation and other therapies such as a drip, a nasogastric tube or a gastrostomy tube, to provide nutrition and fluids. (General Medical Council, UK. (2010). Treatment and care towards the end of life: good practice in decision making. p. 9 [http://www.gmc-k.org/static/documents/content/End_of_life.pdf]

inherently causes secondary lung injury of various degrees, depending on the ventilatory strategies employed and the clinical condition of the patient.⁴⁰

Clinically-assisted ventilation can be delivered via positive-pressure breaths or negative-pressure breaths. Additionally, the positive-pressure breaths may be delivered noninvasively or invasively. Although artificial ventilation techniques have dramatically improved over recent years, many questions remain unanswered, especially in relationship to the appropriate strategy for weaning and extubating paediatric patients from mechanical ventilation.⁴¹

Mortality among patients who require clinically-assisted ventilation is widely variable and dependent on the underlying clinical condition that necessitated the ventilatory support. For paediatric patients with rapidly reversing conditions and who are otherwise healthy, mortality rates approach 0%. Patients with severe acute respiratory distress syndrome suffer 30–60% mortality. Ventilated patients with severe multi-organ system failure and/or severe immunodeficiency suffer 90–100% mortality.⁴² Multiple mechanical ventilation modes are currently used in clinical practice to provide respiratory support for a wide spectrum of patients, ranging from no lung disease to acute lung injury. To date no data exist to determine the ventilatory mode that provides the greatest benefit with the least risk to an individual paediatric patient.

Non-invasive ventilation is defined as the use of a mask or nasal prongs to provide ventilatory support through a patient's nose and/or mouth. By definition this technique is distinguished from those ventilatory techniques that bypass the patient's upper airway with an artificial airway (endotracheal tube, laryngeal mask airway, or tracheotomy tube). Although it is reasonable to attempt non-invasive ventilation in certain patient populations, the vast majority of patients who require ventilatory support need invasive, positive-pressure mechanical ventilation, either conventional or high-frequency.

Similar to the situation with weaning, the ideal extubation timing for the acute lung injury paediatric patient has been elusive, and the techniques used have traditionally been more art than science. As with weaning, extubation involves substantial risks; failed extubation increases the risk of pneumonia, prolongs ICU stay, increases the risk of death, and increases costs.⁴³ Predicting successful extubation of infants and children presents unique challenges to paediatric intensive care clinicians. Currently there are no widely accepted methods for predicting successful extubation in paediatric patients. Many paediatric patients can be "liberated" from mechanical ventilation without a long weaning process.⁴⁴

Clinically-assisted hydration and nutrition

Risks, benefits and burdens

Decisions involving clinically-assisted nutrition or hydration may be particularly difficult and/or contentious, particularly in the case of children. In part, this is because the benefits and burdens of either nutrition or hydration may not be well known and involve difficult assessments of the patient. For example, children in the later stages of a progressive or

⁴⁰ Cheifetz, IM. Invasive and Noninvasive Pediatric Mechanical Ventilation. *Respiratory Care*. April 2003. Vol L

48 No 4, p. 443

⁴¹ Ibid., p. 443

⁴² Ibid., p. 444

⁴³ Ibid., p. 450

⁴⁴ Ibid., p. 452

severely disabling condition, where their body systems begin to deteriorate, may increasingly lose interest in food or drink. For some children, not taking nutrition or hydration may be part of the natural dying process; for others it may not be possible to nurture the child by any other means. Problems in making assessments can arise because of the difficulties in ascertaining the desires of the child for food and fluids. In these distressing situations, the parents may be the best indicator of what the child may want as sometimes the perceptions may differ between doctors, members of the health care team about what the child may be communicating.

It can be extremely difficult to estimate how long a child will live with life-threatening debilitating conditions. Experts in this area of medicine should be sought where the paediatrician or medical officer responsible for the care of the child, or the health care team, are uncertain about decisions around clinically-assisted hydration and nutrition.

Where death is imminent

In judging the benefits, burdens or risks, it usually would not be appropriate to start either clinically-assisted hydration or nutrition where the child is clearly dying. Hydration provided by the less invasive measures may be appropriate where it is considered that this would be likely to provide symptom relief. Where clinically-assisted hydration and/or nutrition are already in use, it may be appropriate to withdraw them if it is considered that the burdens outweigh the possible benefits to the child. Withdrawing clinically-assisted hydration and nutrition must always be discussed with the parent/s of the child or person/s with parental authority, and the child themselves if this is appropriate.⁴⁵

Where death is not imminent

It usually will be appropriate to provide clinically-assisted nutrition or hydration where death is not imminent. However, circumstances may arise where it is clinically determined that a child's condition is so severe, and the prognosis so poor that providing clinically-assisted nutrition or hydration may cause suffering, or be too burdensome in relation to the possible benefits. In these circumstances, as well as consulting the health care team and the parent/s or person/s with parental authority, a second or expert opinion must be sought from a paediatrician or other senior clinician (who might be from another discipline such as a paediatric or palliative nursing professional) who has experience of the child's condition and who is not already directly involved in their care. This will ensure that, in a decision of such sensitivity, the child's best interests have been thoroughly considered, and will provide necessary reassurance to the parents of the child, and to the wider public.

Reaching the decision

In the face of such uncertainties, there may be concern about the possibility that a child who is unconscious or semi-conscious, and whose wishes cannot be determined, might experience distressing symptoms and complications or otherwise be suffering, because their needs for nutrition or hydration are not being met. Alternatively there may be concern that attempts to meet the child's needs may cause avoidable suffering. For parents there may be significant emotional difficulties in deciding not to provide what they see as basic nurture for their child.

Food and fluid should always be offered if the child is able to take it by mouth. Most of the literature around clinically-assisted hydration and nutrition considers the provision of this treatment to be a medical intervention subject to the same benefits/burdens assessment

⁴⁵ Ibid. p. 32

as any other. The insertion of tubes into the gastrointestinal tract carries with it the burdens of discomfort and the potential for complications and therefore needs to be justified on the grounds of the benefits it may provide to the child. An emotive argument also cannot be discounted that the provision of food and fluid constitutes a basic component of humane care and can never be withdrawn or withheld.

In the paediatric setting, this concept is extended by the emotive connection of feeding to the parental role and the vulnerability of children, particularly infants and small children. Children (as well as adults) in the terminal phase of illness will naturally cease eating and drinking as their requirements decrease and it is not necessary in these circumstances to provide fluid and nutrition by artificial means. Parents may find it extremely difficult not to provide sustenance for their child and will require the support of staff. Some parents find their decision is questioned by members of the extended family and friends who are not directly involved in the decision-making processes.

The effect of the provision or omission of clinically-assisted hydration and nutrition on the timing of death is uncertain.⁴⁶ Likewise, the impact of this intervention on patient comfort in terminal illness is poorly understood although emerging data indicates that hydration status and thirst are not related in a predictable way. It is worth noting that dehydration may contribute to opioid toxicity, delirium and constipation and may require correction to ensure the child is kept comfortable.

If there is concern that in the context of maximum comfort of the child that he or she is not receiving adequate nutrition or hydration by mouth, even with support, a further assessment of their condition and their individual requirements must be carried out. A separate assessment of their needs for nutrition and hydration can be carried out and consideration given to what forms of clinically-assisted nutrition or hydration may be required to meet the child's needs.

Blood Transfusions

In Queensland, the *Transplantation and Anatomy Act 1979*⁴⁷ allows blood transfusions to be administered to patients under the age of 18 years in the face of parental refusal of consent, or without the need to obtain parental consent. The provisions require that two doctors must be of the opinion that a blood transfusion is “necessary to preserve the life of the child”. The provisions apply to patients under the age of 18 years and deem blood transfusions carried out in accordance with the legislation be treated as if they have been carried out with the consent of the parent or the person with authority to consent. Importantly, where an older child has the requisite “legal authority” to consent, and refuses to give consent, this can also be overridden by a doctor if the requirements of the legislation are met.

In a particular case,⁴⁸ the parents of a four day old child refused to consent to a blood transfusion to be given to the child after the child developed gastro-intestinal tract bleeding. The parents were from the Jehovah's Witness faith and objected to the transfusion on religious grounds. Despite the objections of the parents the health care team provided a blood transfusion to the child, relying on a provision in the then NSW *Children (Care and Protection) Act 1987*.

⁴⁶ The Royal Childrens Hospital Melbourne. Ethics and Palliative Care – Website [accessed 31 March 2011] http://www.rch.org.au/rch_palliative/prof/index.cfm?doc_id=1682

⁴⁷ S. 20

⁴⁸ *Birkett v Director General of Family and Community Services* (unreported, NSWSC Equity Division, 3 February 1994)

Consent for blood transfusions is, arguably, more straight forward for patients under the age of 18 years than it is for adults. Where the clinical decision to provide a blood transfusion is made in the best interests of the child, this can be provided even without consent provided by the parents or person/s with parental authority. Further discussion of consent and blood transfusions is contained in Legal Considerations – [Consent].

LEGAL CONSIDERATIONS

The law in Australia treats children differently from adults in obtaining consent to the clinical decision to provide, or withhold or withdraw, life-sustaining treatment. While adults can make their own decisions if they have capacity⁴⁹, and a legislative guardianship regime exists to allow for substitute decision-making for adults with impaired capacity⁵⁰, consent requirements for children in Queensland are determined by the common law⁵¹.

Mathews (2010)⁵² has identified three fundamental questions:

1. whether and when a child may consent to his or her own treatment;
2. whether and when parental consent is required; and
3. whether and when court authority is required.

Regardless of the source of the consent, the key consideration at law is the best interests of the child. See [Best Interests].

Certain legal principles applicable to end of life decision-making, and of relevance to children, have been decided by the courts as follows:

1. An act where the doctor's primary intention is to shorten life or cause a patient's death would be unlawful. Euthanasia, either active or passive, is unlawful.
2. Withholding or withdrawing treatment is regarded in law as an 'omission' not an 'act'.
3. Life prolonging treatment may lawfully be withheld or withdrawn from incompetent patients when commencing or continuing treatment is not in their best interests.⁵³ Death following lawful withholding or withdrawal of treatment is due to the underlying disease, not to the omission of treatment.
4. There is no obligation to give treatment that is futile and burdensome.⁵⁴ If a child or their parent seeks treatment that their doctor has not offered, and the doctor concludes that the treatment will not be clinically appropriate to the patient nor in

⁴⁹ Recent Australian decisions confirm the right of competent adult to refuse life-sustaining medical treatment. See *Brightwater Care Group v Rossiter* [2009] WASC 229 and *Hunter and New England Area Health Service v A* [2009] NSWSC 761.

⁵⁰ *Powers of Attorney Act 1998* (Qld) & *Guardianship and Administration Act 2000* (Qld)

⁵¹ The legislative exception to this is the provision of blood transfusions to children under the *Transplantation and Anatomy Act 1979* (Qld), s.20.

⁵² Mathews, B. (2010). Children and consent to medical treatment. In White, McDonald and Willmott. (2010). *Health Law in Australia*. Thomson Reuters: Sydney. p. 117.

⁵³ *Airedale NHS Trust v Bland* [1993] 1 All ER 821.

⁵⁴ *Re J (A Minor) (Wardship: Medical Treatment)* [1990] 3 All ER 930.

their best interests, the doctor is not obliged to provide it. However, they should offer to arrange for a second opinion.⁵⁵

5. In reaching a view on whether a particular treatment would be more burdensome than beneficial, assessments of the likely quality of life for the patient with or without the particular treatment may be one of the appropriate considerations.⁵⁶
6. The 'intolerability' of treatment is not the sole test of whether treatment is in a patient's best interests. The term 'best interests' encompasses medical, emotional and all other factors relevant to the patient's welfare.⁵⁷
7. A patient's best interests may be interpreted as meaning that a patient should not be subjected to more treatment than is necessary to allow them to die peacefully and with dignity.⁵⁸
8. If clinicians and a child's family are in fundamental disagreement over the child's treatment, the views of the court should be sought.⁵⁹
9. When the Court is asked to reach a view on whether it is in an incompetent patient's best interests to withhold or withdraw a treatment, it will have regard to whether what is proposed is in accordance with a responsible body of medical opinion. But the Court will determine for itself whether treatment or non-treatment is in the patient's best interests.⁶⁰

Consent

For children, as for adults, it is generally not lawful to administer medical treatment to a child without consent. This is consistent with the well-recognised bioethical principle of patient autonomy. Depending on the circumstances, consent can be obtained from the child's parent or a person with parental authority, the child themselves, or a court empowered to give consent for the child. If medical treatment is provided without the appropriate consent, it could be both a criminal assault and (civil) trespass to the person.

However, the common law allows for the doctor to administer emergency medical treatment where the child is unable to consent and the child's parent is not available to give consent. This also applies where the child may have been abandoned and is not in the care of a person with parental authority.⁶¹ Medical treatment may include the provision of blood transfusions⁶² necessary to preserve life and any other medical treatment necessary to either preserve life or prevent serious damage to the child's health.

The purpose of consent was aptly described in *Re W (a minor) (medical treatment)*⁶³ -

"There seems to be some confusion in the minds of some as to the purpose of seeking consent from a patient (whether adult or child) or from someone with

⁵⁵ *Re J (A Minor) (Child in Care: Medical Treatment)* [1992] 2 All ER 614; *Burke v GMC* [2005] EWCA Civ 1003

⁵⁶ *Re B* [1981] 1 WLR 421; *Re C (A Minor)* [1989] All ER 782; *Re J (A Minor) (Wardship: Medical Treatment)* [1990] 3 All ER 930; *Re R (Adult: Medical Treatment)* [1996] 2 FLR 99.

⁵⁷ *Wyatt & Anor v Portsmouth Hospital NHS & Anor* [2005] EWCA Civ 1181. *Burke v GMC* [2005] EWCA Civ 1003. *An NHS Trust v MB* [2006] EWHC 507 (Fam).

⁵⁸ *An NHS Trust v Ms D* [2005] EWHC 2439 (Fam). *Burke v GMC* [2005] EWCA Civ 1003.

⁵⁹ *Glass v the United Kingdom* (ECHR, 2004).

⁶⁰ *Re A (Male Sterilisation)* [2000] FCR 193; and *Re S (Adult: Sterilisation)* [2000] 2 FLR 389.

⁶¹ Mathews, B. (2010). Children and consent to medical treatment. In White, McDonald and Willmott. (2010). *Health Law in Australia*. Thomson Reuters: Sydney. p. 115.

⁶² In Queensland, this is also governed by the *Transplantation and Anatomy Act 1979 (Qld)*, s. 20

⁶³ [1992] 4 All ER 627 at 633

authority to give that consent on behalf of the patient. It has two purposes, the one clinical and the other legal. The clinical purpose stems from the fact that in many instances the co-operation of the patient and the patient's faith or at least confidence in the efficacy of the treatment is a major factor contributing to the treatment's success. Failure to obtain such consent will not only deprive the patient and the medical staff of this advantage, but will usually make it much more difficult to administer the treatment. I appreciate that this purpose may not be served if consent is given on behalf of, rather than by, the patient. However, in the case of young children knowledge of the fact that the parent has consented may help. The legal purpose is quite different. It is to provide those concerned in the treatment with a defence to a criminal charge of assault or battery or a civil claim for damages for trespass to the person. It does not, however, provide them with any defence to a claim that they negligently advised a particular treatment or negligently carried it out."

Decisions about withholding and withdrawing life-sustaining medical treatment from patients are also subject to the criminal law, importantly extending to the non-treatment of children. Criminal responsibility may be particularly relevant where life-sustaining treatment is withheld or withdrawn from a child who would otherwise be likely to survive and live a healthy life.⁶⁴

	Adult	Child
Assumption	Capacity to consent	Lack of capacity to consent
Rebuttal	Impaired capacity	Sufficient maturity and understanding to make own decision

As a general legal principle, parents have the responsibility for consenting to medical treatment for their child until the child possesses "a sufficient understanding and intelligence to enable him or her to understand fully what is proposed."⁶⁵ This is referred to as *Gillick*-competency and refers to the point at which a child under the age of 18 years is able to provide his or her own consent to proposed medical treatment.

In *Gillick v West Norfolk and Wisbech AHA [1986] AC 112*, a mother sought to have the court rule that parents and guardians have a right to make decisions on behalf of children as to contraceptive advice or treatment. Mrs Gillick had five daughters under the age of 16, and sought an assurance from her local area health authority that her daughters would not be given advice and treatment on contraception without her prior knowledge and consent while they were under 16. The House of Lords took the view that parental power to consent to medical treatment on behalf of a child diminishes gradually as the child's capacities and maturity grow and that this rate of development depends on the individual child. It also held that the rights of a parent to control their child are for the benefit of the child and recognised only for as long as they are needed for the protection of the child.

The principles established by the House of Lords in the *Gillick* case have since been confirmed by a number of cases in Australia.⁶⁶ For example, in *Marion's* case the court reaffirmed that 'the parent's authority is at an end when the child gains sufficient

⁶⁴ Ibid. p. 483

⁶⁵ *Gillick v West Norfolk and Wisbech Area Health Authority [1986] AC*

⁶⁶ *Marion's* case, *R (A Minor) (Wardship: Consent to Treatment), K v Minister for Youth and Community Services [1982] 1 NSWLR 311*.

intellectual and emotional maturity to make an informed decision on the matter in question.’

Gillick competence test – an assessment of a child’s level of maturity and understanding in relation to particular treatment to be provided, or to be withheld or withdrawn

Even if a child satisfies the *Gillick* test for competency, the child may consent to treatment being provided but cannot refuse consent in the way that an adult can (an adult with capacity can refuse life-sustaining treatment, even if it results in their death). Any refusal of treatment by the child must be in their best interests. Treatment refusals made by those under the age of 18 years may be overridden by the courts. See [Treatment Refusals].

In all decisions relating to withholding or withdrawing medical treatment for those under the age of 18 years, there is a shift from the principle of patient autonomy to that of upholding the best interests of the child.⁶⁷

See [Decision making framework].

Children who lack capacity

Where a child is an infant, so young or lacking in maturity as to be clearly not *Gillick*-competent, the child’s parent/s or a person/s with parental authority have the legal responsibility for making health care decisions for their child. The High Court of Australia confirmed this power in *Marion’s Case* with the majority stating:

“Where their child is incapable of giving consent to medical treatment, parents, as guardians, may in a wide range of circumstances consent to medical treatment of their child who is a minor.”⁶⁸

Exceptions to this legal principle include the following:

- Guardianship orders – where an adult other than the biological parent has been appointed to be the guardian for the child and to make decisions (including those related to medical management) on their behalf and in their best interest (e.g. where the biological parents are deceased)
- Custodial orders – where just one parent has been full custody of the child and / or decision making authority by the courts
- Child Protection orders – due to concerns that the parents are causing harm to their child (including by acts of omission) resulting in the Department of Child Safety being given decision making authority.

Both *Gillick* and *Marion’s Case* confirm that the power to consent to medical treatment is sourced from the common law, and recognise that it is a necessary part of parents’ common law duty to provide the necessities of life. The underlying common law principle is that parents first have a duty to maintain and protect their child, and from this duty is derived the parents’ power to consent to medical treatment for their child.

⁶⁷ Willmott, White & Then (2010). *Withholding and Withdrawing Life-sustaining Medical Treatment*. In White, McDonald & Willmott (2010). *Health Law in Australia*. Thomson Reuters: Sydney. p. 482

⁶⁸ *Secretary, Department of Health and Community Services (NT) v JWB and SMB (Marion’s Case)* (1992) 175 CLR 218 at 239 per Mason CJ, Dawson, Toohey and Gaudron JJ.

Parents or persons with parental authority must make decisions in the best interests of the child.

There may be situations where a parent or person with parental authority refuses treatment that has been proposed. In these situations, the court will need to become involved in decision-making in the best interests of the child. See [Treatment Refusals] and [Dispute Resolution].

There is little judicial guidance in Australia on withholding or withdrawing life-sustaining treatment from infants who may be premature or suffering from a severe congenital condition. Where these children have minimal, or no, prospect of recovery and little chance of improved quality of life, parents may agree to the withholding or withdrawal of treatment if this is in the best interests of the child.

There will be times when parents and clinicians disagree – particularly where clinicians believe it is clinically appropriate for treatment to be withheld or withdrawn and parents wish it to continue – and the court will need to become involved in decision-making in the best interests of the child. See [Treatment Demands] and [Dispute Resolution].

Children with capacity

While the courts acknowledge that children who satisfy the *Gillick*-competency test are able to contribute to, and consent to medical treatment proposed, there is legal debate about whether the position in Australia mirrors that of the United Kingdom. Complex legal debate aside, the common law position in Australia appears to be similar to that in the United Kingdom in that children who satisfy the *Gillick*-competency test may consent to treatment, but a decision to refuse treatment proposed may be overridden by the court⁶⁹. See [Treatment Refusals]

A fixed age for consent?

To address some of the uncertainty around “*Gillick*-competent” children, the Royal Australasian College of Physicians, Paediatrics & Child Health Division states in its policy⁷⁰ that “those over 16 years old should be able to express their preferences about end-of-life care – including the place and situation of their death – and be respected as the main decision-maker”. In addition, NSW and South Australia have provided legislative recognition of the rights of a child over a certain age to make medical decisions on their own behalf.

Notwithstanding this guidance and specific legislation in other States, in Queensland there is no “fixed age” at which a child becomes *Gillick* competent.

The medical officer responsible for the patient’s care must decide whether the child or young person is able to understand the nature, purpose and possible consequences of proposed treatment options, as well as the consequences of not having treatment. Only if

⁶⁹ Supreme Court exercising its *parens patriae* jurisdiction or the Family Court under the *Family Law Act 1975 (Cth)*.

⁷⁰ Royal Australasian College of Physicians, Paediatrics & Child Health Division (2008). *Decision-Making at the End of Life in Infants, Children and Adolescents*.

they are able to understand, retain, use and weigh this information, and communicate their decision to others, can they consent to treatment.

Capacity to consent depends more on the child's ability to understand and weigh up options than on age. When assessing a young person's capacity to consent, the following should be considered:

- Cognitive ability. This may be reflected in the young person's ability to provide a clinical history as well as their understanding of the condition, treatment options and the consequences of choosing one option over another. Other factors to consider include level of schooling, verbal skills and demonstrated capacity to make decisions.
- Presence or absence of disturbed thinking (e.g. in the setting of psychiatric disorder).
- The young person's physical and emotional development and any changes in their health and treatment.

Once a child reaches adolescence it is usually assumed they are competent to make health care decisions on their own behalf. But this will depend on the specific situation, and the complexity and importance of the decision to be made. The health care team should be aware that a young person who has the capacity to consent to straightforward, relatively risk-free treatment may not necessarily have the capacity to consent to complex treatment involving high risks or serious consequences, nor to withholding or withdrawing treatment. In these situations, parents or persons with parental authority should be involved in the decision-making process to ensure that any decision to withhold or withdraw treatment is in the best interests of the child.

Although a Gillick-competent child will have the right to consent to life-sustaining treatment which a clinician wishes to provide, they do not currently have a corresponding right to refuse such treatment. The law in Queensland is not yet ready to remove the test of "best interests" from the equation, and such children will be expected to make "wise choices" until a court decides differently.

Best interests

Regardless of who provides consent, the test of best interests for the child becomes the guiding legal, ethical and clinical principle in all deliberations.

The child's best interests are paramount in end of life decision-making.

Legal precedent for such decisions comes from the United Kingdom in a case heard in 2005 concerning withholding artificial ventilation and intubation from a newborn to avoid the child suffering a collapsed lung.⁷¹

The following factors concerning the child's best interests were outlined by the Court:

The judge must decide what is in the child's best interests. In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the patient ... There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable ... The term "best interests" encompasses medical, emotional, and all other welfare issues ... The court

⁷¹ *Portsmouth Hospital NHS Trust v Wyatt [2005] EWCA Civ 1181*

must conduct a balancing exercise in which all the relevant factors are weighed ... and a helpful way of undertaking this exercise is to draw up a balance sheet.

The determination of best interests in such a case may also take into account whether the child's quality of life is judged to be "intolerable" (which was considered the key consideration in earlier cases), but this will not be the sole factor. It was emphasised that the outcome in each case will be "highly fact specific" and it will be up to the judge to strike a balance between benefit and harm. Factors that may be relevant to a determination of best interests include the medical evidence presented, the options for treatment, the risks involved and prospects of success, and the likely pain and discomfort to be experienced by the child. As the law stands, such cases currently provide the best guidance as to how Australian courts may make decisions in this difficult area.

The term "best interests" is not without its critics.⁷² Tibballs (2006) goes as far as stating that "the term 'best interests' is a nonsense term, or a non sequitur." According to Tibballs, instead of using the test of best interests, it is far preferable to talk of the futility of such treatment, or the overwhelming burden of such treatment, or the lack of quality of life or the artificial prolongation of death that it sustains. To speak of "best interests" in the context of a severely brain damaged infant is meaningless, even counterproductive and obfuscatory, particularly when none exist. While the nature of "best interests" may be defined in various ways, legally the terms "burden versus benefit", "futility", "indignity", "prolonging death rather than saving life" and "quality of life" may have more meaning in the decision-making process.

A parent's power to consent to their child's medical treatment, and to refuse medical treatment for their child, can only be exercised in their child's best interests. The High Court of Australia in *Marion's Case* stated that where the parental power to provide consent to medical treatment exists, two principles apply:

First, the subjective consent of a parent, in the sense of a parent speaking for the child, is, ordinarily, indispensable ... Secondly, the overriding criterion to be applied in the exercise of parental authority on behalf of a child is the welfare of the child objectively assessed. That these two principles become, for all practical purposes, one is a recognition that ordinarily a parent of a child who is not capable of giving informed consent is in the best position to act in the best interests of the child. Implicit in parental consent is understood to be the determination of what is best for the welfare of the child.

Australian courts have repeatedly affirmed the principle that parents may only exercise their authority to consent to, or refuse, medical treatment for their child, in their child's best interests. This is significant because it provides a boundary of powers that parents are able to exercise on behalf of their children. In most cases, the exercise of this power will not be controversial and generally there is little disagreement about the best way forward to ensure a child receives optimal care. However, in some circumstances, parental powers may be limited by the test of best interests to the extent that their powers may be overridden by the courts. In these cases, the Supreme Court can exercise its *parens patriae* jurisdiction and override a parental decision about medical treatment if it's not in the best interests of the child. Examples of this might be where the parents insist on particular regime of treatments for their child and therefore put provisos on their consent, or where parents refuse to consent to medical treatment on their child's behalf; in both cases, the view of the doctors must be that the child's best interests are not being served.

In difficult cases, the task of doctors, parents and courts can be profoundly complex as the various parties navigate their way through what the test of best interests might entail.

⁷² Ibid. p. 260

This is made more complicated as, while courts overseas have deliberated on quite a number of cases where the test of best interests was invoked, this has largely been on a case-sensitive basis and sometimes does not serve the broader test of best interests for other situations. Also, legislative frameworks have not made the task any easier and largely defer the determination of best interests to the substitute decision-makers (even in the case of adults with impaired capacity).

The term “best interests” is used freely in both ethical and legal senses in numerous contexts, but it is a nebulous term and although generally referring to the patient, it may also involve others.⁷³ In Australia, the concept first appeared in *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218 (*Marion’s Case*). The High Court of Australia considered the best interests of a 14-year-old mentally retarded, deaf epileptic girl who was becoming sexually active. Her parents sought court permission to have her sterilised with a non-therapeutic procedure. Among other matters considered by the court was Marion’s “best interests” and who could decide what these were. Mason CJ, Dawson, Toohey and Gaudron JJ stated (at 406):

The decision by a parent that an intellectually disabled child be sterilised may involve not only the interests of the child, but also the independent and possibly conflicting (though legitimate) interests of the parents and other family members ... Subject to the overriding criterion of the child’s welfare, the interests of other family members, particularly primary care-givers, are relevant to a court’s decision whether to authorise sterilisation. However, court involvement ensures, in the case of conflict, that the child’s interests prevail.

These judges acknowledged that the “best interests of the child” test is imprecise, but no more so than the “welfare of the child”, and foresaw that its meaning would develop. Brennan J also acknowledged the difficulty of defining “best interests”, and that the real benefit of the use of the phrase was a focus on the child: “the best interests approach is useful only to the extent that the first and paramount consideration is the interests of the child, not the interests of others” (at 423). He offered a rationale for the lack of a definition at the time the case was decided (at 421):

[T]he best interests approach offers no hierarchy of values which might guide the exercise of discretionary power to authorise sterilisation, much less any general legal principle which might direct the difficult decisions to be made in this area by parents, guardians, the medical profession and courts ... and it must be remembered that, in the absence of legal rules or a hierarchy of values, the best interests approach depends upon the value system of the decision-maker. Thus the views of parents are taken into account but the main attention should always be on the “best interests” of the child, not on those of other parties.

Pursuant to s 68F of the *Family Law Act 1975* (Cth), a court, in determining what is in a child’s best interests, must consider any wishes of the child, relationships with parents and others, any changeable circumstances, the child’s maturity, protection from physical and psychological harm and any other matters considered by the court to be relevant. In Britain and Australia, parents and medical staff are required to determine together the “best interests” by considering the advantages and disadvantages of treatment and of non-treatment (burden versus benefit), the quality of life, the purpose of treatment, or its lack (futility). Where there are disputes about the best interests of a child, they must be brought before the courts who will decide.

⁷³ Tibballs, J. (2006). The legal basis for ethical withholding and withdrawing of life-sustaining medical treatment in children. *Journal of Law and Medicine*. 14(2): 244-261.

Participation in Decision-making

Even if young children are unable to provide their own consent, they have a right to be informed regarding decisions which affect their future. Furthermore, it is important that a child's inability to communicate or participate does not mean that their suffering is excluded from benefits/burdens considerations.

The requirement to respect the rights of young people comes from national and international conventions.⁷⁴ Therefore all members of the health care team should listen to and respect children and young people's views about their health and consider how best to support them to reach an understanding of the clinical issues, so far as they are able. They should be involved as much as possible in discussions about their care, whether or not they are able to make decisions for themselves. Information about their diagnosis and prognosis should be provided in a manner that they are able to understand, unless they (or their parents) do not want this information to be given, or if you judge that giving the information might cause them serious distress. In this context 'serious distress' means more than the child becoming upset or deciding to refuse treatment.

Treatment refusals

Parents of children who lack capacity may try to reject life-sustaining medical treatment on religious grounds (e.g. refusal of blood transfusions based on their Jehovah's Witness faith) or due to personal beliefs (e.g. a preference for alternative remedies).

In Queensland, blood transfusions can be administered to children where consent has been refused or has not been able to be obtained.⁷⁵ The *Transplantation and Anatomy Act 1979* requires that two medical practitioners have the opinion that a blood transfusion is necessary to "preserve the life of the child". Blood transfusions carried out under this Act are treated as if they have been carried out with the consent of the parent or person with parental authority.

Children with capacity may also try to refuse treatment which clinicians consider to be clinically appropriate. A *Gillick*-competent young person cannot refuse life-sustaining treatment, where the provision of that treatment would be in their best interests (including where the parents agree with their child's decision). However, overriding a refusal is not taken lightly and a court would take into account the views of the child.⁷⁶

For example, in *Minister for Health v AS (2004) 33 Fam LR 223*, the Supreme Court acknowledged the 15 year old patient was *Gillick*-competent, however overturned the decision of the patient to refuse a blood transfusion. In that case, the 15 year old patient was a practising Jehovah's Witness and in line with the beliefs of that faith, refused to consent to blood products.

The section [Dispute Resolution] will also assist in navigating a way forward in terms of treatment refusals.

⁷⁴ UN Convention on Rights of the Child

⁷⁵ *Transplantation and Anatomy Act 1979* (Qld), s.20.

⁷⁶ See comments in *Minister for Health v AS (2004) 33 Fam LR 223*

Treatment demands

When a child is faced with a life-threatening illness or injury, this triggers protective impulses in parents who struggle with the unfairness of the situation and the loss of life's opportunities for their child. These protective instincts often manifest themselves in the need to advocate strongly for their child, and sometimes to insist on treatments which are 'futile' or not in their child's best interests. Paediatricians, and other health professionals, can also have similar impulses as their practice will usually involve providing treatments which result in cure or prolongation of the children and young people they treat. This can sometimes result in health professionals offering treatments which are not in the child's best interests based on their sense of failure and disappointment at not being able to cure the disease of the child or young person they are treating.

Neither parents nor a *Gillick*-competent child can demand a particular treatment that is not in the child's best interests. Equally, a clinician is not obliged to offer or provide treatment that is not in the child's best interests.

The section [Dispute Resolution] will also assist in navigating a way forward in terms of treatment refusals.

DECISION-MAKING FRAMEWORK

Children's inability to act autonomously and their necessary reliance on parents as decision-makers complicate the resolution of ethical questions in paediatric practice. There are occasions when parents insist on treatment that health professionals view as inappropriate. Conversely, parents may refuse treatment of potential benefit to the child. A child's inability to communicate or participate must not mean that the child's suffering is excluded from considerations of benefits or burdens. Decision-making should involve the child (where possible), the family, and all the health professionals providing care with the key focus: the best interests of the child.

A child's ability to make informed choices depends on his or her life experience, cognitive ability and level of maturity. A seven year-old child with a chronic illness, may, through his or her illness experience, be better positioned to participate in decision-making than an older child with no significant medical history. Child preferences and insights may guide decision making by others even if a child is not deemed sufficiently competent to act autonomously. The Royal Australasian College of Physicians (Paediatrics and Child Health Division), the Royal College of Paediatrics and Child Health (United Kingdom) and the American Academy of Pediatrics strongly advocate the participation of children in decision making to the extent that their ability allows. With an existing condition, gradual or sudden deterioration may be anticipated, and the goals of care should be renegotiated and documented regularly. While it may seem difficult to raise some issues when a child is reasonably well, it is generally helpful to plan care in advance to avoid decision-making in a crisis. Positive planning emphasises interventions the child and family *do* want rather than things they *don't* want. It also has the potential to empower family members and help them regain a sense of control.

Reviewing decisions

A child's condition may improve unexpectedly, or may not progress as anticipated, or their views about the benefits, burdens and risks of treatment may change over time. Every effort should be made to ensure that there are clear arrangements in place to review decisions. New decisions about commencing or continuing with a treatment may be needed in the light of changes in the child's condition and circumstances, and it may be necessary to seek a second opinion or, if this is not possible, advice from an experienced colleague with expertise in this area.

A1 In the best interests of the child, clinical decision is made, in collaboration with the health care team, to withhold and/or withdraw life-sustaining measures.

This is the commencing premise for the flowchart, based on clinical judgement that further active medical treatment for the child is inappropriate. In reaching such a critical decision, the clinical judgement for further active treatment always comes first.

The paediatrician or medical officer responsible for care of the child uses evidence-based practice, specialist knowledge and experience, and clinical judgement, and where possible the views of the parent/s or person with parental authority, to reach an understanding of their condition and identify which investigations or treatments are clinically appropriate and likely to be in the best interests of the child.

Such a clinical determination may also be based on whether further active medical treatment is “futile”. That is, with the child’s best interests at the forefront of decision-making, whether there is an imbalance between benefits and burdens and further interventions will be clinically inappropriate, burdensome and indeed harmful to the child.

However, this first step comes with an important proviso that the clinical decision to withhold or withdraw life-sustaining measures does not exclude the provision of other medical interventions and palliative support therapies. The provision of comfort measures is obligatory.

A2 Acute Emergency

This decision point is if there is no time to obtain consent and the life and health of the child are critically compromised. In acute emergency situations, there is no expectation that inappropriate clinical interventions will be provided until consent to withhold such measures is obtained.

In acute emergency situations, clinical judgement based on the circumstances at the time will apply.

A3 Non-acute clinical situation. Discuss proposed treatment plan with parent/s and where appropriate, child.

In non-acute clinical situations it is presumed there is sufficient time to obtain the appropriate consent. The paediatrician or medical officer responsible for care of the child and parents (or person/s with parental authority) makes an assessment of the child’s condition, taking into account the child’s medical history, views, experience and knowledge. As far as practicable, the child should be involved in the decision-making commensurate with their willingness, maturity and cognitive development.

If the child has sufficient maturity to understand the nature and effect of the decision to withhold or withdraw medical treatment, then consent, legally, can be obtained from them – See box C3.

The paediatrician or medical officer responsible advises the parent/s or person with parental authority that consideration is being given to withholding or withdrawing life-sustaining measures from the child on the basis that further active medical treatment is clinically futile. The utmost care and compassion should be extended to the parents during this difficult discussion and the paediatrician or medical officer responsible should:

- avoid using the word “futile”, as this has subjective connotations which could be counter-productive to the relationship with the parents, and potentially detrimental to the child;
- explain the achievable options to the child’s parents, in the presence of the child, if this

is appropriate;

- set out the potential benefits, burdens and risks of each option;
- include a broad assessment of the child's best interests as part of the treatment plan;
- be mindful not to pressure parents into accepting their clinical advice, particularly at first discussion;
- allow sufficient time for the parents to absorb the information;
- propose further family conferences to discuss proposed treatment plan, if this is appropriate.

The parents, in consultation with the child, as appropriate, weighs up the potential benefits, burdens and risks of the various options as well as any non-clinical issues that are relevant to them as a family. The decision is made to accept any of the options and, if so, which ones.

It should be noted that parents are best to gauge whether it may be appropriate for their child to be present at this discussion. While children of any age should have knowledge about their condition and prognosis, the parents may be best placed to recommend the best timing for this to occur. Bear in mind, however, that a "Gillick-competent" child is able to consent to medical treatment and therefore the discussion about available options must include the child as a non-negotiable.

A4 A dispute resolution process should be commenced without delay if parents or child insist on clinically inappropriate treatment.

If the parent/s or person with parental authority or a child (who may be "Gillick-competent") insist on treatment and interventions that the paediatrician or medical officer considers would not be clinically appropriate, nor in the best interests of the child, a family conference should be called as soon as practicable to discuss the issues and explore the reasons for their request. Similarly, if the parents of the child or person with parental authority refuse to consent to medical treatment that the doctor believes the provision of that treatment would be in the best interests of the child, then this situation *must* be resolved as quickly as possible.

If, after the initial discussion, the paediatrician or medical officer still considers that the treatment would not be clinically appropriate, there is no obligation to provide the medical treatment. This is based on the legal and ethical principle that health providers are not obliged to provide medical treatment considered contrary to the standards of good medical practice, will be harmful, provide no benefit, and in all respects, is clinically "futile".

While it is recognised that "acceptance" time may be needed for parents to absorb tragic news, continuing to provide futile treatment against the standards of good medical practice may have the perverse effect of increasing the potential for risk of liability. For example, this could occur where further medical treatment for a dying child exacerbates the clinical situation, leading to the child being left in a post coma unresponsive state directly as a result of the treatment demanded. The parents or person with parental authority may lodge a formal complaint that this is not the outcome they expected, potentially exposing the health care team and the hospital to risk of liability because the standards of good medical practice were not adhered to.

Doctors or health providers are not obliged to accede to requests or demands by adults (or children) for clinically inappropriate medical treatment that is assessed as not being in the best interests of the child.

The reasons for the decision to withhold and withdraw treatment should be explained to the parent/s and child where appropriate, and any other options that are available, including the option to seek a second opinion or access to legal representation. Parents may refuse any of

the options presented on behalf of their child, including disagreeing with the medical opinion to withhold or withdraw medical treatment. Equally, children may also demand treatment that will not improve their condition, nor allow them to recover. Technically, disagreeing with the clinical decision to withhold or withdraw medical is equivalent to demanding clinically inappropriate treatment. However, as with every decision to withhold or withdraw medical treatment, palliative and comfort measures must be provided.

If family conferences do not reach an acceptable conclusion, an appropriate dispute resolution process must be commenced without delay. This could include a range of measures, each one escalating the issue to a point where a resolution may be reached. For example, following unsuccessful family conference meetings, consideration should be given to obtaining expert advice from a person not associated with the health care team. Hospital administration should also be informed of the dispute if it cannot be resolved within what would be considered a reasonable timeframe. Consideration could also be given to involving the district lawyer and hospital ethics committee at any time during the dispute, depending upon the circumstances of the case. Of course, the best interests of the child must always be paramount, and if the dispute cannot be resolved within what would be considered reasonable time limits, an application must be made to the Court with the appropriate clinical recommendation.

A5 Provide medical treatment in accordance with Court decision.

Unless the district is prepared to lodge an appeal, the decision reached by the Court is final. If the Court overturns the clinical recommendations and determines that providing medical treatment is in the best interests of the child, this must be carried out in strict accordance with the detail in the Court Order. In these situations, meticulous documentation is required.

A6 Review and monitor child's condition. Create new care plan.

Where the decision of the Court compels the hospital to provide medical treatment for the child, this must be done in strict accordance with the Court Order. A new treatment plan, based on the Court's decision will be required. In such cases, the child's condition must be reviewed and monitored according to the treatment provided. In such circumstances it could be presumed that the child's condition will remain serious and advance toward worsening health.

Where the child's life and health reaches the point where consideration is again given to withholding or withdrawing active medical treatment, the steps must be followed according to the flowchart. The clinical decision to withhold and withdraw life-sustaining measures in the best interests of the child must always come first. This is why reviewing and monitoring is linked to the first box (A1) in the flowchart, as none of the steps as described (for example, consent) should be omitted in the decision-making pathway.

C1 When obtaining consent, take child's views and wishes into account, where appropriate.

This is the beginning premise for consent to health care by a child. In all cases, it is highly recommended to involve children, as far as this is practical and possible, in decisions about their future health care. If it is considered that a child has sufficient maturity to understand the nature and effect of the decision, they may consent to the health care being provided as proposed by the paediatrician or medical officer responsible. Involving the child must be in their best interests, and the paediatrician and medical officer, in consultation with the child's parent/s or person with parental authority, will be best placed to determine the appropriate level of involvement and timing of involvement of the child in decision-making.

Assessing whether a child has sufficient maturity to understand the nature and effect of

decisions about health care requires finely-balancing a range of complex issues, including age, cognitive development and presence of factors that may impede capacity. The test that applies in the legal context emerged from a 1985 legal case heard in the UK. In *Gillick v West Norfolk and Wisbech Area Health Authority* [1985] 3 All ER 402 (HL) it was found that the authority of parents to make decisions for their children is not absolute, but diminishes with the child's evolving maturity.

The term “*Gillick*-competent” is now commonly used to describe older children and adolescents (under the age of 18 years) who are considered to have sufficient maturity and cognitive development to consent to health care and contribute to health care decisions on their own behalf. While a number of more recent cases have confirmed the judgement set down in *Gillick*, the cases do not specify the age at which a child is regarded as competent, as this is unique for every circumstance. The paediatrician or medical officer, together with the parents of the child, are best placed to determine whether a child is competent. Of course, it may be quite obvious that a young person, of say 17 years, is competent to discuss and consent to their own health care decisions. This becomes less certain to ascertain if a child is, say 10 years of age.

While it could be argued that, legally, a “*Gillick*-competent” young person may consent to the clinical decision to withhold or withdraw life-sustaining measures, the gravity of the situation must involve a higher test of “maturity to understand the nature and effect of the decision.” Since this area of decision-making is profoundly difficult and involves complex interactions to establish what is in the best interests of the child, Queensland Health’s policy is that parent/s or person/s with parental authority must also be involved in the discussions and subsequent decisions about life-sustaining measures.

C2 – Consent is not required provided the decision is in the child’s best interests and impractical to obtain consent.

This is a direct result of an acute emergency situation. Where it is not possible to obtain consent of the parent/s or person/s with parental authority, the paediatrician or medical officer responsible must exercise his or her best clinical judgement based on the facts of the case and the circumstances involved. In all cases, the decision-making must support the best interests of the child.

When time is of the essence, and the child’s medical condition is so grave that it is determined the clinical decision to withhold or withdraw life-sustaining measures is the only option, this can be followed through in the best interests of the child, without obtaining consent from the parent/s or person/s with parental authority.

Meticulous documentation is required in such cases. Where the child has a PARP, the consenting details provided on the form may be sufficient to provide consent to withhold or withdraw medical treatment. Where there is no PARP in place, it is highly recommended that two (2) medical officers indicate in the patient’s record the circumstances leading to the decision to withhold and withdraw life-sustaining measures.

C3 - Consent is always required - from parent/s or person with parental authority or child with sufficient maturity to understand the nature and effect of decision.

In non-acute routine clinical situations, it is presumed there is sufficient time to discuss an appropriate treatment plan for the child. If the treatment plan involves withholding and withdrawing life-sustaining measures, palliative support and comfort cares must be provided – this is obligatory. As outlined in C1, obtaining consent in these situations is not necessarily

straight forward. Legally, if a child is “Gillick-competent”, then consent can be obtained from the child for health care treatment. If the child is not competent by reason of age or disability, then consent for health care will be required from the parent/s or person/s with parental authority.

The guardianship legislation contains consenting provisions to withhold or withdraw life-sustaining measures for those over the age of 18 years. Decisions around life-sustaining measures are considered to be of such a serious nature that specific provisions and protections apply and are enshrined in the law. Queensland Health’s policy position on withholding and withdrawing life-sustaining measures for those under the age of 18 years, is that because these decisions involve matters of life and death and the best interests of the child, consent should be obtained from both the child (even if they are “Gillick-competent”) and the parent/s or person/s with parental authority).

Consent to medical treatment in the end-of-life area is complex, and has two aspects; *providing* (positive), and *not providing* (withholding/withdrawing - negative). For positive medical treatment that is proposed by the paediatrician or medical officer, consent may be obtained from the “Gillick-competent” young person without parental involvement. This is largely because consent to *provide* positive medical treatment to any competent patient under the age of 18 years is relatively straight forward – the focus is positive - saving the life and health of the child. Therefore, if the child is competent, he or she can consent to the medical treatment as proposed. An example of this might be to set a compound fracture for a 17 year old following a motorcycle accident. In such a case, there would be no requirement to seek the consent of the young person’s parents.

For consent to *not provide* (withhold or withdraw medical treatment in the context of resuscitation planning), the focus is no longer on active medical treatment to save the life and health of the child because such interventions are no longer in the child’s best interests. For a Gillick-competent child to consent to withholding or withdrawing life-sustaining measures, it is presumed that the clinical decision has already been made to be in their best interests. Because the decision to withhold or withdraw life-sustaining measures will ultimately result in the death of the child, it would be considered in the best interests of child to involve their family support network in such a momentous decision.

The competent young person, can of course, refuse to provide consent to medical treatment proposed, which is when the legal and ethical issues collide. It must be noted that the legal position for treatment refusals operate differently between adults and those patients under the age of 18 years.⁷⁷ For children, treatment refusals are linked to the test of best interests, rather than autonomous consent. While a competent young person may consent to medical treatment to be provided, legally, they may not refuse medical treatment that is in their best interests. Parent/s or person/s with parental authority would need to be involved in treatment refusals. An example of this is where the Gillick-competent child refuses to consent to withholding or withdrawing medical treatment. In other words, they are requesting or demanding futile medical treatment that is not considered to be in their best interests. In such cases, the parents or person with parental authority must become involved, however the parents or person with parental authority do not automatically become the default “decision-maker”, because ultimately the best interests of the young person must be served. If the matters are unable to be successfully resolved through family conferences and mediation, referral to the Supreme Court or Family Court would be required.

⁷⁷ Adults have the right to refuse medical treatment for reasons that may seem irrational to the doctor or for no reason at all. This decision must be followed, even if the doctor believes it is not in the best interests of the adult patient. Adults have the right to refuse medical treatment even if this results in their death.

C4 If consent cannot be obtained, application must be made to the Supreme Court or Family Court.

As discussed in C3, withholding and withdrawing medical treatment is about *not providing*. This makes the act of obtaining consent far more complex, because it requires consideration by all involved of the child's imminent death. Decisions involving withholding and withdrawing medical treatment are so grave that it is Queensland Health's policy position that parent/s or person/s with parental authority must be involved in these discussions. Even for young people who are "Gillick-competent", making such decisions in isolation of their family support network would be considered counter-productive to patient-clinician relationships as described in the Medical Board's Code of Conduct for Good Medical Practice.

Similarly with adults, the effect of a competent young person's refusal to provide consent to withholding or withdrawing life-sustaining measures amounts to a demand for futile medical treatment (against their best interests). Since health providers are not obliged to provide medical treatment that offers no benefit and may cause harm (i.e. futile), this issue would drill down to what is in the best interests of the young person. In such cases, the parents do not automatically become the default decision-maker. Where the young person and his or her parents and the health care team do not agree on an appropriate clinical treatment plan in the young person's best interests, the matter must be referred to the Courts. However, while this point is raised in the context of discussion about possibilities, it is considered extremely rare and highly unlikely.

C5 Court provides consent (Court Order) in accordance with clinical opinion.

Once a matter is referred to the Family Court or Supreme Court, the deliberations will focus on the best interests of the child. The Court will take a range of matters into consideration, including the clinical recommendations as well as issues involving personal and family situation. In some more complex matters, judgements may involve requesting a "balance sheet" which outlines the benefits and burdens of the clinical decisions proposed. In the case of MB,⁷⁸ Justice Holman considered such a document in his deliberations. The balance sheet consisted of two columns with "benefits" (such as, possible/probable recognition of his parents and siblings and some pleasure/comfort in their presence [extent of ability to experience pleasure uncertain]) on the one side, and "burdens" (such as, MB cannot move his body, head, arms or legs, although has some very restricted "flickering" movement in his thumbs and some of his fingers and possibly foot) on the other.

Irrespective of the judgement provided by the Court, the decision is final. The health providers will be required to follow the directions and instructions outlined "to the letter". Appeals may, of course, be made to overturn the judgement, but until this occurs, the decision of the Court must be followed. Meticulous documentation will be required in these cases.

Importance of recording decisions

Ensuring open and frank communication between the health care team and the parents of the child will limit the situations where medical officers are asked to provide what would constitute potentially futile treatment. Decisions to withhold and withdraw life-sustaining measures made solely on clinical grounds must be strongly justified and thoroughly

⁷⁸ An NHS Trust v MB [2006] EWHC 507 (Fam) (15 March 2006)
<http://www.bailii.org/ew/cases/EWHC/Fam/2006/507.html>

documented. Careful attention to recording (in the charts and progress notes) details of the clinical circumstances and events leading up to the decision to withhold medical treatment is required by professional standards and the law. It is highly recommended that a second opinion from another senior medical officer/consultant be obtained in cases where the parents of a child insist on “everything to be done” and it is not considered good medical practice to do so.

Any handover arrangements should be checked to ensure that the agreed care plan is shared within the health care team, with both paid and unpaid carers outside the team and with other health professionals involved in providing the child’s care. This is particularly important if the child moves between different care settings (hospital, ambulance, home) and during any out-of-hours period. Failure to communicate some or all relevant information can lead to inappropriate treatment being given.

Dispute Resolution

Understanding disagreement

There may be exceptional circumstances where one or other party holds completely rigid views with an unshakeable confidence in the rightness of their beliefs. It is hoped that all professionals and most parents will accept that in issues of this magnitude and complexity there is always some degree of uncertainty. In the figure following, provided by Tripp and McGregor (2006) in their article on *Withholding and withdrawing of life sustaining treatment in the newborn*, this uncertainty is shown where the decision to treat or not to treat is plotted against the expected severity of outcome or expectation of inevitable early mortality (or both). As the authors point out, the part of the hypothetical graph where such a decision is at least debatable is shown by divergence of the two lines.

Problems in communication

Hilden and colleagues observe that physicians report anxiety about discussing an impending death with children and their parents (Hilden et al., 2001). Anxiety and dread may interfere with a thorough assessment of a child’s emotional and spiritual well being and careful evaluation of child and family circumstances (e.g. cultural values, religious beliefs). Inadequate assessment may, in turn, compromise timely efforts to identify and relieve physical and emotional distress.

Clinicians’ anxiety may also contribute to poor communication about the child’s situation and prognosis, which may deprive children and families of information they need to plan for the future and weigh the pain or other suffering expected from an intervention against its probability of meaningfully extending a child’s life. Certainly, most paediatric specialists have less experience than similar adult specialists in communicating a grim prognosis, although both groups have little or no training in this task.

Clearly, the most difficult decisions, and those with the greatest chance of being unable to reach a consensus decision, are in the area where the lines are furthest apart. Ultimately this is a dichotomised decision: to treat or not to treat. The graph is representing where the greatest collective uncertainty exists. This is where fewer individuals or groups will immediately agree to the solution.

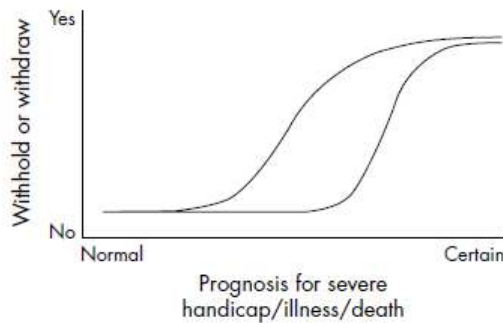
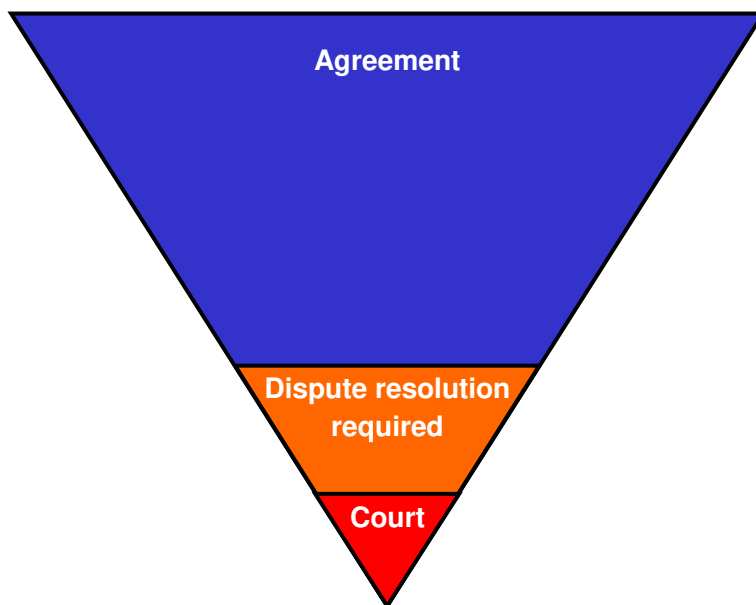


Figure reproduced from Tripp & McGregor (2006), p. F68.

Figure 1 Parents and professionals may have similar views at either end of the graph but in the area of most uncertainty they may have different views.

Other researchers as well as personal stories also point to physician anxiety and confusion about communicating bad news and discussing death and dying. Although most of these studies involve adult patients and families, it seems reasonable that some of the problems they identify will apply to communication involving children with life-threatening conditions. If physicians cannot face fully a child’s poor prognosis and then appropriately communicate their assessment to families, timely re-examination of the goals of care and corresponding adjustments in care plans may be delayed.

Society invests parents with the responsibility of acting on behalf of their children. There are occasions however, where parents insist on what staff may view as inappropriate treatment. Conversely, parents may refuse treatment that is of potential benefit to the child. It is important that the test of best interests is at the core of every decision, decision-making is shared between the parents and the health care team, and that all become advocates for the child’s best interests.



As can be observed from the following figures, the cases that proceed to Court are significantly rare. Most disagreements can usually be resolved by open and honest communication through a resolution process that focuses on the best interests of the child and respecting the differing opinions of the parent. Time is the greatest ally in such circumstances and must be factored into the decision-making process. As such, decision-making should be viewed as a process rather than an event. Families often

need time to absorb and process difficult information. Where conflict can not be resolved in what would be considered a reasonable amount of time, it may be helpful to request a second opinion from an independent health care professional. It may also be beneficial to include other family members or cultural and religious leaders from the local community. In circumstances where agreement is not able to be reached despite a number of attempts, it may be necessary to commence a process that may lead to the Court providing its determination.

Situations where disputes may be likely

Disagreement between parents and health care professionals about the most appropriate treatment for their child may arise in many circumstances. For example, parents and doctors may disagree when either the parents or the doctor are in favour of continuation (or of withholding/withdrawal) and the other opposed. Disagreement may result from personal interpretation of, or group adherence to, less prevalent religious beliefs. The latter include those of Jehovah's Witness faith, who have major concerns about the use of blood, or some sects of the Jewish faith, who have major anxieties about the process of withdrawal (an act of commission) as opposed to withholding treatment (an act of omission).⁷⁹

Most individuals are able to accept the premise that we should not act to cause an outcome that is unacceptable to the individual to whom the treatment is to be applied (a consequentialist argument). Others will see an overriding obligation not to participate in any action that either directly or indirectly causes death of another human (this being either a duty based or deontological argument). Health care professionals might more often take a consequentialist ethical view based on their clinical experience of the potentially profound future problems for people with very severe impairments.⁸⁰ Parents may take a deontological perspective; that is, their position is justified on moral grounds, emanating from a sense of duty, rather than focusing on the benefits or risks of their decision. These two bases of ethical decision-making often result in different conclusions as to the ethical solutions. When parents and health care professionals are basing behaviours on different ethical paradigms, disagreements are likely. It is also possible for a health professional to hold a deontological perspective and for a parent to hold a consequentialist ethical view.

Further areas of disagreement may arise from different interpretations of the principle of autonomy. For example, neonates are not autonomous so the responsibility for decision-making passes to their parents. This creates potential for difference of opinion with professionals, who may feel that they have a better appreciation of the best interests of the infant.⁸¹ Disagreement may also arise simply from a difference in evaluation of the medium or long term prognosis and treatment options, particularly for infants. Even having reached an agreed understanding of the infant's potential for physical survival and prognosis, there may be disagreement about whether a life of this expected quality is considered worthwhile and of value. It may be that the interests of the parents, for example, the fulfilment of a profound desire for a child of their own, may be perceived by professionals to be contrary to the best interests of the infant.⁸²

When the family wants information to be withheld from the child

Apart from circumstances in which a patient refuses information, you should not withhold information necessary for making decisions (including when asked by someone close to the patient), unless you believe that giving it would cause the patient serious harm. In this context 'serious harm' means more than that the patient might become upset or decide to refuse treatment. If you withhold information from the patient, you must record your reasons for doing so in the medical records, and be prepared to explain and justify your

⁷⁹ Ravitsky V. Timers on ventilators. *BMJ* 2005;330:415–17.

⁸⁰ Tripp, J. & McGregor, D. (2006). Withholding and withdrawing of life sustaining treatment in the newborn. *Arch Dis Child Fetal Neonatal Ed* 2006;91:F67–F71

⁸¹ McHaffie HE, Laing I, Parker A, et al. Deciding for imperilled newborns: medical authority or parental autonomy? *J Med Ethics*. 2005;27:104–9.

⁸² Tripp, J. & McGregor, D. (2006). Withholding and withdrawing of life sustaining treatment in the newborn. *Arch Dis Child Fetal Neonatal Ed* 2006;91:F67–F71

decision. You should regularly review your decision and consider whether you could give information to the patient later, without causing them serious harm. Health professionals will need to abide by a parent's request not to tell the child about their condition. At the same time, they can also discuss with the parents or person with parental authority that no health professional will lie to the child if the child directly asks them a question.

When the family doesn't want to know

Some patients may not be ready to think about their future care, or may find the prospect of doing so too distressing. However, no-one else can make a decision on behalf of an adult who has capacity. If a patient asks you to make decisions on their behalf or wants to leave decisions to a relative, partner or friend, you should explain that it is important that they understand the options open to them, and what the treatment will involve. If they do not want this information, you should try to find out why. If the patient still does not want to know in detail about their condition or the treatment, you should respect their wishes as far as possible. But you must explain the importance of providing at least the basic information they need in order to give valid consent to a proposed investigation or treatment. This is likely to include what the investigation or treatment aims to achieve and what it will involve. For example, whether a procedure is invasive; what level of pain or discomfort they might experience and what can be done to minimise it; what they should do to prepare for the investigation or treatment; and whether it involves any serious risks.

If the patient (or parent) insists that they do not want even this basic information, you must explain the potential consequences of carrying out an investigation or treatment if their consent may be open to subsequent legal challenge. You must record the fact that the patient has declined relevant information and who they asked to make the decision about treatment. You must also make it clear that they can change their mind and have more information at any time.

Parental refusal of treatment

As medical care becomes more complex, so do the types of legal problems arising out of parental refusals of treatment. Some refusals stem from religious convictions; for example, some Jehovah's Witness members object to blood transfusions for children as well as adults. Other refusals are based on a parental view that a child with a serious illness (such as cancer) should not be subjected to the side effects of treatment and that "alternative therapies" offer as much benefit as chemotherapy without the side effects. Some parents, who accept the fact that their child is probably dying, want to stop painful or other unpleasant treatments to prolong the child's life in an effort to provide as much peace as possible. A recent case⁸³ in the United States highlights this point as a mother is accused of attempted murder in connection with the 2009 death of her son who died from respiratory complications related to his leukaemia.

"Massachusetts General Hospital doctors had given the boy an 85 to 90 percent chance of surviving the non-Hodgkins lymphoma he was diagnosed with in 2006 if he followed a two-year treatment plan, prosecutors said. But those chances diminished to just 25 to 30 percent with a bone marrow transplant after Dr. Alison Friedmann discovered in 2008 that his disease had developed into leukemia."

⁸³ State of Massachusetts v. LaBrie – 4 April 2011.

The Jury heard that the chemotherapy prescriptions were filled only three times in eight months, arguably, leading to the premature death of the nine year old. Judgement on the case is still pending.⁸⁴

Court intervention, based on the legal principle that failure to provide the “necessaries of life” for a child is a violation of the law or criminal code,⁸⁵ is always an option if physicians consider it appropriate. Religious conviction is never a defence for a refusal to provide medical care for a child. For example, if a 3-year-old child of a Jehovah’s Witness is in an automobile accident, needs a blood transfusion to which the parents object, and is expected to recover completely, section 20 of the *Transplantation and Anatomy Act 1979* provides protections for doctors and other members of the health care team if the blood transfusion “was necessary to preserve the life of the child.” Similarly, if a child had acute appendicitis but his parents refused to consent to any medical care at all, the child could be operated on without obtaining consent from the parents, who could face charges under a number of sections under the *Criminal Code 1899 (Qld)*.⁸⁶ When the need for life-saving treatment is urgent, a medical officer or health provider will not be liable in the face of the parental objection, as long as it is clear that there was no time to apply for and receive a court order. See [Legal Considerations] for more information on parental treatment refusals.

If a child’s life is not *immediately* threatened, even if the underlying condition is desperately serious, most courts’ longstanding practice is to refuse to order that high-risk therapies be given over parental objection. This raises the prospect that if a court order is obtained to provide life-sustaining medical treatment for the child, the child will have to be either hospitalised during the entire period or removed under court order from his parents and placed in foster care. To inflict this on a family and a child at a time of suffering and perhaps impending death is something that should be considered only under the most extraordinary circumstances and when there are strong reasons to believe that the achievable goal is long-term remission or a potential cure. If the health care team is confronted with parents who, for whatever reason, are “uncooperative” may assume correctly that a court order can be obtained to treat the child. The ultimate question is whether such a step will, on balance, benefit the child. In many situations, it will not.

Parental insistence on treatment

By far the more common and the opposite of the situation described above, is where parents insist on medical treatment for their child because they refuse to accept the inevitability of their child’s death. Conflict arises in these situations when the paediatrician or medical officer responsible for the care of the child feels that further aggressive life-prolonging interventions for a dying child are futile or will cause suffering in excess of any potential benefit and the parents refuse to accept that decision. Some but not all of these conflicts arise when parents, for religious or other reasons, will not accept the concept of brain death.

If a patient (child or adult) is, by standard medical criteria, brain dead, no permission is required to pronounce the patient dead, provided declaration of death is carried out in the

⁸⁴ The Associated Press, Boston Herald and Herald Media. 5 April 2011. Laura Crimaldi. *Doctor testifies about mom accused of withholding meds.*

[<http://www.bostonherald.com/news/regional/view.bg?articleid=1328628> – accessed 12 April 2011.]

⁸⁵ Section 286 *Criminal Code 1899 (Qld)*

⁸⁶ Section 286 *Criminal Code 1899 (Qld)*.

proper manner.⁸⁷ Even if the family objects, the neurologist or neurosurgeon may sign the death certificate and then remove the respirator (thus demonstrating that the patient was dead *before* life support was removed).⁸⁸ In most circumstances, however, paediatricians and medical officers may find it advisable to obtain a court order before terminating life support over parental objections. One of these circumstances is when the child's condition is or may be the result of abuse inflicted by the parent.⁸⁹ When a parent will face a murder or manslaughter charge as soon as the child is pronounced dead, he or she will almost never consent to withdrawal of life support (AAP, 2000). Since the circumstance of pronouncing the child dead will be the major issue in the parent's trial, it is important to have a clear record of the circumstances, including a judge's order to terminate life support, even if the child meets all criteria for brain death.⁹⁰

In most litigation involving parental insistence on treatment, the child is not brain dead but most likely is in a post-coma unresponsive state. In these cases, a paediatrician may determine that further medical interventions will provide no benefits to the child, that any hope of recovery and continued maintenance of the child on life-support is futile. In contrast, the parents of the child are simply thankful that he or she is "not yet dead" and refuse to allow termination of life support. Even if they agree with the paediatrician's judgment that there is no hope of improvement, they may take the position that if the child is not dead, he or she is still alive and should receive all the treatment that can be provided.

It is increasingly clear that where there are conflict situations, or where it is predicted a conflict situation will arise, before withholding or withdrawing life-sustaining measures from a child, doctors should begin a conflict resolution process, and depending upon the circumstances, apply to the Court. Second opinions, involving objective experts, mediation, and ethics committee consultation may help mitigate the issues and might persuade the parents or person with parental authority to change their minds, particularly if the basic problem is the parents' lack of trust in the doctors or hospital system. It should be born in mind that the findings of an ethics committee have no legal standing and cannot be used alone as the basis for termination of life support.

Parent-child conflict

Based on their experience, many physicians recognise that even very small children know when they are very sick and are often far more aware of death than adults may realise. Medical and nursing care of seriously ill children includes helping them to achieve a developmentally appropriate understanding of their illness and making sure that they know what to expect from tests and treatments. Their views should be taken seriously, but these views may or may not be the deciding factor in decision-making about the child's future treatment options.

Young children are rarely, if ever, asked if they want the medical care their doctor and parents or person with parental authority decide is best for them. No one asks a four year old if he wants an injection. He is told that he is going to get one and what it will feel like.

⁸⁷ Section 45 *Transplantation and Anatomy Act 1979*; *Lovato v. District Court*, 198 Colo 419, 601 P 2d 1072, 1979; *Alvarado by Alvarado v. New York City Health and Hospitals Corporation*, 145 Misc 2d 687, 547 NYS 2d 190, 1989

⁸⁸ *Law v. Camp*, 116 F Supp 2d 295, 2000, 2001 WL 868354, CCA 2, July 27, 2001.

⁸⁹ *In re L.H.R.*, 253 Ga 439, 321 SE 2d 716, 1984; *In re M.D.*, 758 A 2d 27, DC CA 2000.

⁹⁰ (*Truselo v. Carroll*, 2000 WL 33324536, Del Fam Ct 2000; *In re Tabatha v. Ronda R.*, 252 Neb 687, 564 NW 2d 598, 252 Neb 864, 566 NW 2d 782, 255 Neb 818, 587 NW 2d 1909, 1998; *In re Haymer*, 115 Ill App 3d 349, 450 NE 2d 940, 1983; see also *Massie*, 1993; *Fleming*, 1999).

(A child can still be offered choices such as which arm to use and can still be advised on what he or she can do to make it hurt less.) However for older children and adolescents, the issues are more complex.

When parents and an older child or adolescent patient disagree, the doctor becomes the patient's, not the family's, advocate. If the prognosis is poor and the patient has "had enough," the doctor is professionally obligated to do everything she or he can to persuade the parents to abide by the child's view and wishes. Therapies that the doctor considers inadvisable may not be provided based solely on the request made by distraught parents. On the other hand, if the prognosis is good but the patient does not want to continue therapy, the doctor's responsibility is to understand and respond to the child's fears and guide her or him through the treatment.

The Gillick-competent child is able to consent to medical treatment, but unlikely to refuse medical treatment proposed to be in their best interests (See further explanation of competent children and consent in [Legal Considerations]. Interestingly, the United States has adopted a position that distinguishes *consent* to medical treatment from *assent* to medical treatment. The American Academy of Pediatrics provided a policy in the late 1990s describing the process of securing assent (consistent with the child's stage of development) recommended to include at least:⁹¹

- (1) helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition;
- (2) telling the patient what he or she can expect with tests and treatment(s);
- (3) making a clinical assessment of the patient's understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy); and
- (4) soliciting an expression of the patient's willingness to accept the proposed care.

The policy statement stressed that patients should have the opportunity to provide assent to care whenever reasonable and that children and adolescents should not be excluded from decision-making without persuasive reasons. The policy statement also commented on a child's refusal to assent, or dissent, stating that there are clinical situations in which a refusal to assent may be ethically binding. However, the statement was clear that the child should not be led to believe that his opinion will affect treatment decisions in situations where treatment needs to be undertaken regardless of the child's wishes.⁹²

Parent–parent conflict

Although there may be instances in which parents are bitterly divided on the wisdom of continuing life-sustaining treatment for a child who is likely to die, the situation may be reasonably straight forward, legally. If there is a conflict between two persons with parental responsibility over consent to medical treatment for a child, then attempts should be made to resolve the disagreement through a family conference, involving objective experts or other family/community representatives as appropriate and as time permits. If the situation becomes intractable, it may be necessary to seek a court order to resolve the situation.

⁹¹ Lee, K J et al. (2006). Assent for Treatment: Clinician Knowledge, Attitudes, and Practice. *Pediatrics* 2006;118;723-730. p. 724

⁹² *Ibid.* p. 724

Resolving disagreements

If disagreements arise about what course of action would be in a child or young person's best interests, it is usually possible to resolve them by, for example, involving an independent advocate; seeking advice from a more experienced colleague; obtaining an independent second opinion; by holding a case conference or ethics consultation; or by using local mediation services. If, after taking such steps, significant disagreement remains, you should seek legal advice on applying to the appropriate court for an independent ruling. Approaching the court should be seen as a constructive way of thoroughly exploring the issues and providing reassurance for the child and parents that the child's interests have been properly considered in the decision.

Strategies to maximise an ethical conclusion

Paediatricians will usually be the first to recognise when they are facing a decision about whether or not life-sustaining medical treatment will be beneficial for a child who is under their care. It is less likely that parents will be in a position to do so, at least initially, or that other members of the health care team will arrive at a decision at the same time. An open discussion of this uncertainty by the health care team with the parents will avoid highly divisive perceptions. Parents may have a perception that a decision has "already been made" and the team are simply looking for parental endorsement or that it is a "them and us" situation. A single answer should be reached (to continue or withdraw) and conveyed by the senior medical officer responsible for care of the child. Often these are not dilemmas that "solve" and there may be no black or white answer that feels "right" to everyone. Helping all involved to recognise this from the start allows time for reflection and coming to terms with solutions to which individuals may originally have been strongly opposed. Parents may feel that the possibility of withdrawal of active medical treatment from their child comes as a complete surprise after their prognostic enquiries have been met with relatively optimistic outlooks. Therefore it is highly advisable that a level of openness about uncertainties for treatment is raised at the earliest possible time. Early team discussion and planning of how to communicate a deteriorating clinical picture to parents is vital, especially while there is still considerable uncertainty. It is often said that many parents simply do not "hear" the, possibly slightly coded, negative statements.⁹³

Parental views should carry strong weight and are usually determinative unless they conflict seriously with the interpretation of the child's best interests by those who are providing care.⁹⁴ In strictly legal terms, when there is an irresolvable disagreement, parents, while having the legal right to consent to treatment for their children, do not have an absolute right either to refuse treatment judged to be in the best interests of the child or to demand futile treatment to sustain the life of their child.⁹⁵

Health professionals should bear in mind that the UN Convention on the Rights of the Child clearly spells out the responsibilities of society to support parents in the application of their beliefs and in their ultimate position of prime responsibility for the welfare of their children.⁹⁶ If professionals are uncertain to any degree, then there is sufficient uncertainty for them to accept the determinative responsibility of parents. Only when convinced that the parent's view is one that a reasonable person could not support should they consider referral to court to determine what the child's "best interests" are. Such arbitration has a

⁹³ Tripp, J. & McGregor, D. (2006). Withholding and withdrawing of life sustaining treatment in the newborn. *Arch Dis Child Fetal Neonatal Ed* 2006;91:F67–F71. p. F69.

⁹⁴ British Medical Association Ethics Department. (2003). *Medical ethics today: the BMA's handbook of ethics and law*, 2nd ed. London: British Medical Association, 2003:131–64.

⁹⁵ England and Wales high court of justice: family division. Portsmouth NHS trust v Wyatt & ors.

⁹⁶ UNICEF website. Convention on the rights of the child. <http://www.unicef.org/crc/>

role in ensuring that the medical community checks that its moral views remain in line with those of society.

The other side of the equation is that by adhering to the standards of good medical practice, clinicians should have the right to determine how and when their skills are used. If they feel that use of those skills is going to cause unacceptable suffering, they must be allowed to withdraw their service, and object on the grounds of conscience. If this decision is made, there is a responsibility to encourage the parents to seek help from another professional or group. Regularly seeking a fully informed and independent second opinion within or from outside the treatment unit may help either party to recognise the validity of the other's view. Such advice may perhaps come, for example, from a colleague with similar religious beliefs to the parents such as a "priest" or elder from their religion, as recommended in the framework.

Nationally or internationally recognised guidelines for care (based on research evidence, best practice or expert opinion) can also help to inform decision making.^{97, 98} There can be some limitations of the use of guidelines. This includes the accepted practice documented may be surpassed by improving clinical care and technology over time and hence need to be interpreted with such a lens. Further, guidelines for one country or jurisdiction may not be totally appropriate to the context of a different country or jurisdiction. Another example of a guideline is that related to withdrawing nutrition from children which has been published by the American Academy of Paediatrics.⁹⁹ Interestingly these guidelines suggest consultation with a Bioethics Committee when particularly difficult or controversial decisions are being considered.

It is hoped that by working with parents in decision making about end of life care, there is sharing of responsibility, and mutual agreement on the best resuscitation and overall management plan. Some parents may prefer to be less involved in making or owning the decisions and this should also be acknowledged. Although both parents and professionals have rights, it is usually going to fall to the professional team, who have to take the actions resulting from the decision, to elicit how much of their "rights" parents want to exercise, bearing in mind the responsibility and potential for guilt that comes with a right of determination. "Exploratory" work with parents is required to discover how they wish the final decision to be made and how much responsibility they wish to take.¹⁰⁰ The professional description of the decision can vary from "these are the facts and we are

⁹⁷ For example, the Nuffield Council on Bioethics has made recommendations about resuscitation and continuing intensive care of extremely premature infants. Chiswick M. (2008). Infants of borderline viability: Ethical and clinical considerations. *Semin Fetal Neonatal Med* 2008;13(1):8-15.

⁹⁸ In Australia, a consensus statement exists regarding decision-making about newborns of borderline viability. This framework considers the gestational "grey zone" to be between 23 and 25 weeks. The guidelines make recommendations in alignment with the Nuffield recommendations but essentially leave initiation of treatment to the discretion of parents and treating clinicians for newborns at the threshold of viability. Lui K, Bajuk B, Foster K, Gaston A, Kent A, Sinn J, *et al* (2006). Perinatal care at the borderlines of viability: A consensus statement based on a NSW and ACT consensus workshop. *Med J Aust* 2006;185(9):495-500; Darlow B (2006). The limits of perinatal viability: Grappling with the "grey zone". *Med J Aust* 2006;185(9):477-9; Forbes M (2011). Should artificial resuscitation be offered to extremely premature neonates. *Australian Medical Student Journal* 2011;2(2): 86-89.

⁹⁹ Douglas S. Diekema, Jeffrey R. Botkin, Committee on Bioethics (1999) . Forgoing Medically Provided Nutrition and Hydration in Children. *Pediatrics* 1999; 124(2): 813 -822

¹⁰⁰ Tripp, J. & McGregor, D. (2006). Withholding and withdrawing of life sustaining treatment in the newborn. *Arch Dis Child Fetal Neonatal Ed* 2006;91:F67-F71. p. F69.

asking for your decision” to “we have now come to a conclusion as to what is the best course of action and are looking for your consent to carry it through”.¹⁰¹

Parents may not want to feel that this responsibility is actually ever allocated, preferring that a consensus appears to be an equally shared responsibility. Some may not wish to be put in a position where they have to say yes or no at all, even within a group decision. To follow through with decided actions means that clinicians are putting themselves at risk of later recrimination, a risk that not all professionals are willing to take. With protections afforded to health professionals, this sort of risk taking is highly professional. The professional’s willingness to take responsibility for the decision is likely to be an important mechanism to allay parental guilt. Some parents may actually welcome the opportunity to be completely relieved of the decision and turn to the courts. However, this occurrence is rare, and the Courts generally recognise the difficulties faced in making such decisions.

In decisions relating to withholding or withdrawing medical treatment, a plan of action with which neither party is altogether happy may be the best that can be achieved. This is firstly because there is a real dilemma with no “good” or “right” answer, but only a “best”, and secondly because parental autonomy must be respected, unless it clearly and unarguably contravenes the infant’s rights. Reassurance from colleagues, experts, ethical committees, and, exceptionally, the court can be immensely valuable to the decision making process. For advisors beyond the immediate team to go further and prescribe their own preferred course of action may deny the personal autonomy of both parents and professionals. This is clearly unhelpful in the immediate situation.

From the above discussion it is clear that professionals acting in this area of clinical practice require a number of specialist skills that have not been traditionally formally taught in either the undergraduate or postgraduate curriculum. In the “traditional” medical education experienced by most consultants, ethical questions were often simplified, sometimes to the extent that they were reduced to an understanding of the Hippocratic Oath and Beauchamp and Childress Principles of Biomedical Ethics. This deficit is recognised and increasingly addressed at both levels of education. Many undergraduates now receive some formal teaching in relation to the underlying principles of ethical decision making. Most medical postgraduates in paediatrics will expect to have a practical framework for the way in which they give bad news.

In relation to communication skills, both are likely to have received formal training, and recent candidates will have been assessed. Addressing difficult communication in such situations can often require a broad knowledge and reflective application of ethical, medical, sociological, biological, and psychological principles in highly stressful environments and highly charged situations. Senior doctors are often counsellors, facilitators, providers, and gatekeepers— roles that are often in opposition to each other. As team leaders they must be open to the perspectives and positions held by others, especially parents, but also members of the whole team of professionals. They should be prepared to negotiate and explore the relevant issues in order to reach the best possible and most inclusive consensus decision.

¹⁰¹ Ibid. p. F70

PART 2

ETHICAL CONSIDERATIONS

Ethical obligations at an individual level

Ethical obligations at the collective level

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Quality of life

Respect for the child's developing autonomy

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How can risk of harm be minimised?

What is futility?

Futile medical treatment and euthanasia – the difference

Futile medical treatment and the law generally

What is the doctrine of double-effect?

How should I respond to requests for euthanasia?

What is the meaning and value of death?

Can I abstain from treating a child on the basis of conscience?

COMMUNICATION

Delivering bad news

Bad news in the ED

Death of a child in the ED

Bad news in the delivery room

Addressing the concerns and anxiety of parents

Talking about death and dying

Talking to parents

Talking to children

Children 2 to 5 years of age:

Children 6 to 9 years of age:

Children 10 to 12 years of age:

Talking to adolescents

Advance care planning for children

What to discuss

Recording the child's wishes in an advance care plan

Medical decision-making and goals of care