



**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 2

Ethical Considerations and Communication

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PART 2

ETHICAL CONSIDERATIONS

Introduction

Questions and disagreements about what constitutes appropriate medical treatment for infants and children suffering from severe or life threatening medical conditions are frequent topics in the bioethics literature and occasionally gain a higher-profile through litigation and reported, sometimes sensationally, in the media. A key goal for caring for dying children is to minimise avoidable conflicts that can arise as a result of failures in communication, insufficient attention to goal setting and care planning, and inappropriate clinical care. Continued efforts at the individual and the organisational level can contribute to the prevention and resolution of conflicts about clinical care, for example, by defining procedures for identifying and managing situations that pose high risks for conflict, developing and testing communication protocols to prevent or defuse conflict, establishing procedures for ethics consultations (or, in some cases, family counselling), and providing ethical guidance that clarify decision-making around benefits and burdens of medical interventions in different clinical situations.

Modern medicine and intensive care has provided an increased ability to prolong life where it may not always be appropriate to do so.¹ There is a duty to ask not only whether we treat a condition because we *can*, but also question whether we *should*. For treatment that has already commenced, we should also ask whether it should continue where it provides no discernible benefit other than keeping a body alive. These are questions that only society as a whole can debate to reach a conclusion that is acceptable to the majority. The answers will not come from individual medical, legal or ethics experts, nor from politicians, the media, our places of worship or their spiritual leaders, although individuals and representatives from these groups may provide some leadership and expertise. The issues around dying children are so ethically complex that responses from all these groups must be considered in the collective sense.

Our doctors and health care teams grapple with such issues every day; balancing respect for autonomous rights with providing the most beneficial outcomes, promoting the best interests of their patients while allocating resources based on the varying but unique needs of all patients, all the while maintaining clinical integrity and meeting the standards of good medical practice. The decisions that emerge from balancing these issues have an overriding objective: to help people sustain the life and health that are essential to their total well being, including their ability to make their own decisions and to achieve an acceptable level of independence. Our society expects that clinical judgement, the rule of law and ethical practice will be at the highest standard and consistently applied to all patients, irrespective of age, gender, culture, condition or prognosis.

Turning once again to the questions posed above (i.e., do we do it just because we can?), we may find that on a personal level, there is no emphatic absolute and, arguably, nor might this be such a bad thing. The internal discomfort we may experience responding to such questions corresponds to the polarised views in our society - largely because they concern attitudes about the value of life and the meaning of death. We may deduce signs about the appropriateness of our private answers from whether they accord with such things as; established clinical practice standards, accepted cultural values,

¹ Wellesley, H. & Jenkins, IA. Withholding and withdrawing life-sustaining treatment in children. *Pediatric Anesthesia* 2009 19: 972–978

legal statutes, religious codes, accountability standards for managing resources fairly and equitably and, importantly, whether the lives of patients improve. However, as society continues to confront such challenging questions, the arguments for and against work their way into public consciousness. We gradually become accustomed to the issues around such questions through media attention, political platforms, laws that are debated and then introduced, and the policies produced by our health and welfare authorities.

The purpose of raising these most vexed questions is for the reader to examine, and perhaps even question, their own perspective and moral view. The overwhelming message emerging from much of the bioethical literature on such topics in the last few decades is that while modern medicine has enabled humanity to experience enormous advances in treating the body *physically*, there are limits to such advances, *ethically and morally*. This is why, when end-of-life decisions are required (particularly in the case of children), it is understandable why such emotional and seemingly irrational responses can emerge. Some of this can be attributed to our socialisation; in that, each individual has a unique perspective derived from their own personal meaning system as impacted upon by events and experiences in their own life. For example, some people hold the view that the 'sanctity of life' is absolute, and therefore there is a duty to preserve the life of the child at all costs. Those who do not hold the absolutist view of the sanctity of life accept that there are situations where it is permissible to consider withholding or withdrawing medical treatment. Those in the second group may also hold that a patient's autonomous right to control their own destiny is absolute. While people that strongly hold either position rarely agree on a middle ground, there are nuances and variances between the extremes that may be helped by ethical considerations.

In the case of those patients under the age of 18 years, such considerations are made all the more difficult because, legally, statutes² that protect those with impaired capacity are only available to adults, that is, patients who have reached the age of 18 years. For those patients aged under 18, common law precedents and the test of best interests is the overwhelming "decider". If the child is capable of contributing to their future health care decisions, they are said to be "Gillick-competent" (the age of about 10 years). Yet if it is determined the decisions the child is making are not in their best interests, parents or doctors (through the courts) can overturn such decisions. (See Legal Considerations for further discussion of competency and consent)

There is little doubt that end-of-life decision-making involving those patients under the age of 18 years is perhaps one of the most difficult areas in medicine. While dying children and their parents may face the same profound issues at the end of life as adults do, there are unique ethical and moral aspects specific to children. One area of ethical consideration which is unique to paediatrics is that relating to the "zone of parental discretion"³. Further, the principles of child-centred and family-centred care also offer a holistic approach to dealing with many of these issues with families⁴. For a whole host of reasons, most of which fall outside the scope of these guidelines, the imminent death of a

² *Guardianship and Administration Act 2000 and Powers of Attorney Act 1998*

³ Gillam L, Sullivan J. Ethics at the end of life: who should make decisions about treatment limitation for young children with life-threatening or life-limiting conditions? *J Paediatr Child Health*. 2011 Sep;47(9):594-8

⁴ Meert KL, Clark J, Eggle S. Family-centered care in the pediatric intensive care unit. *Pediatr Clin North Am*. 2013 Jun;60(3):761-72.

child is viewed differently to the imminent death of an octogenarian. When children are involved in tragic circumstances, parents may feel torn as they balance: the unconditional love they have for their child⁵, the nurturing role nature and society has bestowed upon them, acting in best interests of the child they are responsible for, and accepting the limitations of medicine.

The imminent death of a child is viewed as outside the natural order of life. Children represent hope, vitality, and health. Viewed in this way, a child is seen in terms of his or her potentiality for the future. A dying child challenges the interpretations we have about life, faith, and certainty in the future. For health care providers and families of dying children, questions abound. Have all curative options for the child been exhausted? When and how should the child and family be told of the prognosis? How will the pain and distress of dying be managed by the health care team and the family? Who should make the decisions regarding whether to continue treatment or turn solely to end-of-life care? Who should manage the terminal care? Is it ethically appropriate to stop treatment? What will dying be like for the child? For his or her family? For the doctors and nurses providing care?

While parents have legal rights to make decisions on behalf of their children, the extent to which children become involved in their care and the limits placed on a parent's decision making can be controversial.⁶ Many people believe that "parents know best" when it comes to their children and that parental decisions should prevail. However, others argue that parents may sometimes not be objective when it comes to making treatment decisions for their child. The suggestion has been made that while parents should be consulted, they perhaps should not always have the final word about treatment decisions, particularly for adolescents.⁷ It is Queensland Health's policy that children to the extent of their abilities should be encouraged to participate in decisions about their own care.

Ethical obligations at an individual level

Clinicians' own beliefs and values play an important role in assisting the families to cope with a dying child. Clinicians should take time to reflect on their personal experiences with death and dying and bear in mind that no two families will experience the imminent death of their child in the same way. However, amidst these difficult decisions, clinicians need not feel isolated and unsupported. Assistance comes in the form of accepted positions, obtained through complex ethical and legal arguments, reinforcing how our society functions by balancing such things as patient autonomy and distributive justice with medical supremacy. Society as a whole has determined its legal and ethical positions on such matters in numerous documents it has agreed to; international and national conventions concerning human rights, national and state legislation, significant legal precedents from case law, and standards of good medical practice overseen by health professional regulatory bodies. Therefore, taking all this information together, we can be confident that drawing upon this material provides a valid starting point. For example, it is generally accepted that there are limits to what medicine can offer. From this we can safely assume that in some cases it would be unacceptable to continue to provide medical treatment where it causes harm and offers no benefit. Gauging benefit versus harms in these circumstances is not only determined by clinical judgement, it is also assisted by ethical and moral principles held by each member of the health care team.

⁵ Gillis J, Rennick J. Affirming parental love in the pediatric intensive care unit. *Paediatr Crit Care Med.* 2006; 7(2):165-8

⁶ Field MJ, Berman RE, (Eds.) 2003. *When Children Die: Improving Palliative and End-of-Life Care for Children and their Families.* Institute of Medicine Series. Washington, D.C.: The National Academies Press.

⁷ Freyer DR. Care of the dying adolescent: special considerations. *Pediatrics* 113 (2) February 2004:381-388.

At the individual level, ethical analyses generally focus on the obligations of clinicians, first, to patients and, second and less often, to parents, the child's extended family and support network. Notwithstanding the child's age, most issues related to their care can be considered within the same broad ethical frameworks that are applied to caring for adults. During recent decades, general agreement has emerged on the core ethical obligations of clinicians to patients.⁸ In plain terms these obligations are to:

- do good – by always acting in the child's best interests, eg., by relieving a child's pain or providing emotional support (*Beneficence*);
- avoid doing harm - by not providing inappropriate or unwanted life-sustaining treatments that impose burdens on a child without benefit (*Non-maleficence*);
- respect patient autonomy - by generally attempting to consider care "through the child's eyes" even if the child is not competent to consent (*Autonomy*); and
- treat patients equitably - by seeking to provide or arrange needed care for children regardless their condition, age or of their family's ability to pay (*Distributive justice*).

These ethical obligations may sometimes be in conflict and may not be equally weighed in practice. For example, a single action may involve both benefits and harms that have to be balanced in view of the child's overall circumstances and understood preferences. The obligations to avoid harm and to respect autonomy have been exhaustively considered in debates about withholding life-sustaining treatment. Other obligations or other formulations of clinical and, more generally, medical ethics exist. Ethicists may, for example, cite the obligations of "fidelity" and "professional integrity." Fidelity is the responsibility of health care professionals to place the interests of their patients first. Professional integrity can be viewed as a broad obligation of clinicians to act ethically in all their relationships and to be faithful to their moral values when they are challenged. The Medical Board of Australia has developed guidance for clinicians around meeting the standards of good medical practice.⁹

A few observations about clinical ethics in this context can be offered. First, good communication and consensus building strategies should usually help clinicians to do good for parents (for example, by helping parents to feel they have done their best for their child); avoid harming parents (for example, by helping them avoid choices they will later regret); and treating parents fairly (for example, by providing understandable information and generally respecting their values). Second, in most situations, when clinicians fulfil their obligations to a child of doing good, avoiding harm, and treating fairly, they are doing likewise for parents because parents usually want to advance their child's best interests.

Most discussions of clinical and medical ethics focus on the obligations of individual professionals rather than health care teams. As discussed further in these guidelines, different members of a child's care team may sometimes have different views of what constitutes ethical care. Although medical officers usually have the legal and professional authority to prevail, the persistence of unresolved and unacknowledged conflict can compromise the implementation of decisions, damage health team members, and subtly (sometimes explicitly) undermine patient and family trust in health team members. Some

⁸ Beauchamp TL & Childress JF. (2009). *Principles of Biomedical Ethics*. (6th Ed.). Oxford University Press: New York. Jonsen A & Toulmin S. *The Abuse of Casuistry: A History of Moral Reasoning*. Berkeley: CA. University of California Press. McCullough L. (1998). *Preventative ethics, managed practice and the hospital ethics committee as a resource for physician executives*. HEC Forum 10: 136-51.

⁹ *Good Medical Practice: A Code of Conduct for Doctors in Australia*, Medical Board of Australia, 2009. <http://www.medicalboard.gov.au/Codes-Guidelines-Policies.aspx>

conflicts may reflect individual values, characteristics, and personalities; others may be systemic, variously acquired through societal norms and professional values.

Ethical obligations at the collective level

Clinicians may sometimes perceive their obligations to their patients individually to be in conflict with their obligation to do good or avoid harm for patients collectively. To cite a dramatic but atypical example, in emergency departments and critical care units, an unusual surge in injured patients may outstrip available personnel, space, and equipment. In response, clinicians and others have established triage protocols to guide decisions about how to allocate sometimes scarce treatment resources in such situations. Debates about the appropriate use of limited resources arise across the spectrum of clinical decisions and are sometimes at the crux of ethical obligations.

However in the paediatric context, some of the most widely publicised disagreements about resource use focus on care for extreme preterm infants who have conditions that even with treatment are incompatible with extended life or with neurological function beyond the most primitive level.¹⁰ An American case from the 1990s, appearing in many bioethics discussions is that of “Baby K.” The debate surrounding that particular case raised questions about the limits of parental demands on community resources and on health providers who are convinced that such demands violate their professional ethics and integrity. In this case, the mother of an anencephalic child (who lacked all parts of the brain except the brain stem) insisted on repeated resuscitation attempts. Federal trial and appellate courts held that ‘emergency’ care could not be denied under the federal laws. However it should be noted that this case, although providing some interesting context, is not binding on Australian courts. This case and other cases relevant to demands for inappropriate medical treatment are further discussed in Legal Considerations and also in Communication.

Often, clinicians may join with parents in a desire to “do everything” to prolong the life of a dying child, including providing some treatments of marginal or no benefit. They may argue that such care provides emotional comfort and hope to the parents and allows all involved freedom from any guilt they might experience had they not pursued every option. In other cases, the paediatrician may resist such treatment because they believe it harms the child, violates their clinical values, and misuses limited health care resources. These clinicians may, however, accept that it is humane to provide a limited amount of care that cannot benefit a patient but that can reduce the suffering of family members. Thus, even when a child is, by clinical criteria, brain dead, a doctor may delay removal of life support to give parents time to absorb the information, to come to terms with the decision to remove life-support equipment, and to say their good-byes in peace. While the provision of medical treatment in these instances may be futile in the short term, arguably, it buys much needed time for the parents of the child (and in some cases for the child) to come to terms with the decisions that are made.

The allocation of resources for medical care is just one element of a broader set of issues of about the allocation of community resources and responsibilities. It should also be kept in mind that families of a seriously ill or injured child often must shoulder heavy financial burdens, sometimes extending to job loss, home loss, bankruptcy, and homelessness. Even if they have private health insurance, it will usually not cover all the home health care and non-medical home care and other services needed by a child and family. Medicare and other government programs may cover more services but, in many cases, only after a family’s resources are virtually exhausted.

¹⁰ Fost N. (1999). Decisions regarding treatment of seriously ill newborns. *JAMA*. 281:2041–2043.

Exploring ethical themes

The purpose of this section of the document is to navigate through some of the more complex arguments, providing an ethical framework within which clinicians may find reassurance as well as practical advice. From the outset it must be stated that no single ethical framework is likely to embrace all views on end-of-life decision-making, particularly around questions of withholding or withdrawing medical treatment for those patients under the age of 18 years. The literature supports this statement and provides for a number of general themes when incorporating ethical considerations in this area. These general themes are as follows:

1. The best interests of the child
2. Respect for the child's developing autonomy
3. Respect for parents as decision-makers for the child
4. The well-being of the family
5. Respect for the child's privacy
6. Respect the privacy of the family
7. Fair and equitable resource allocation

Following the discussion under these seven general themes, some broader ethical issues will be canvassed under the heading: Moral Questions. The material posed by each of the questions prompts the reader to challenge his or her own moral position on the issues, potentially providing a more thorough ethical perspective for decision-making in this area. The issues raised under Moral Questions are as follows:

- What does it mean to respect human life?
- What is benefit?
- How can risk of harm be minimised?
- What is futility?
- What is the doctrine of "double-effect"?
- What is the meaning and value of death?
- How do I respond to requests for euthanasia?
- Can I abstain from treating on the basis of conscience?

The best interests of the child

"Best interests" involves weighing the benefits, burdens and risks of treatment, in order to achieve the best possible outcome for the child or young person. Indirectly, the value of the life of the child is judged during the time a decision is needed, arguably making the test of best interests, at least, partially subjective. While the word "interest" is in common usage across diverse fields from commerce, banking and industry to education, politics and government, the term "best interests" has its roots in the law, moral philosophy and ethics. It refers to those things which are needed to have a good or virtuous life, and suggests a number tenets for which a person can aspire to. Used in the context of responsibility for protecting others, particularly those who are vulnerable in our society, it means using the highest principles to ensure a person unable to fully contribute to their well-being is supported to the best or most optimal extent possible. In the field of medicine, it encompasses the bioethical principles of beneficence and non-maleficence. Assessing a person's best interests includes taking account of physical matters, such as

not suffering or being in pain, and minimising distress. The test for best interests also includes social and emotional factors, such as enabling interactions with other people, feeling safe, and having the capacity to contribute to relationships. Future best interests are particularly relevant to children and adolescents – these are things that will matter significantly to their lives, even though they do not matter to them at the moment, such as achieving personal goals, associating with peers, and having close or intimate relations.

To act in a child's best interests is to do whatever will best promote all the child's interests. It is a maximising concept – doing the best possible for the child overall. However, since a child has a range of unique and important interests, there should also be a realistic element to protecting their best interests - it is not always possible to fulfil all interests all of the time. For example, if a child has an interest in being pain-free and in living longer, it may not be possible to have both. Acting in a child's best interests can be a matter of working out the best compromise, or deciding between competing considerations, in consultation with the child, to the best of their ability, and also with the child's parent/s. Acting in a child's best interests should not necessarily be equated with prolonging the child's life for as long as possible. It is widely recognised that it is not always best for a child live longer, nor is a child necessarily harmed by dying sooner than might have been possible with the full application of available medical technology. This position is recognised both in ethical discourse, and the law.

The complexity around this concept makes judgements of best interests not a straightforward factual matter, particularly where end-of-life decisions are concerned. Reasonable people working on the same evidence can disagree, either because they have different views about probabilities of possible outcome, or more likely because they have different values and therefore operate from a different meaning system. That is, the conflict about what is in a child's best interests often stems from emotional and societal values held by all those involved in the decision-making, including those of the health care team. For example, upholding the principle that the sanctity of life is absolute may be at the cost of alleviating suffering. Such decisions are never easy to reach and sometimes the two (or more) positions will not be entirely compatible. It must also be considered that while the various decision-makers are debating about what is in the child's best interests, the child's condition may well be worsening and their best interests unprotected.

Identifying the best interests of children or young people who may be approaching the end of life can be challenging. This is particularly the case when there are uncertainties about the long-term outcomes of treatment when emergencies arise, and in the case of extremely premature neonates whose prospects for survival are known to be very poor. Complex and emotionally demanding decisions may have to be made; for example, about whether to resuscitate and admit a neonate to intensive care, and whether to continue invasive intensive care or replace it with palliative care. It can be very difficult to judge when the burdens and risks, including the degree of suffering caused by treatment, outweigh the benefits of the treatment to the child.

To aid in establishing what is in a child's best interests, the Nuffield Council on Bioethics proposed five factors that should be considered:¹¹

1. The degree of pain, suffering and mental distress that treatment is likely to inflict, or is inflicting on the child.

¹¹ 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>

2. The likely future benefits the child might get from treatment. Will the child be able to survive independently of life support, be capable of establishing relationships with other people and be able to experience pleasure of any kind?
3. The extent to which treatment is likely to effect a significant prolongation of a child's life (as opposed to simply prolonging the dying process).
4. The level of support likely to be available to assist in long-term care for the child.
5. The views and feelings of the parents as to the interests of the child.

Taking these factors into consideration, an attempt must be made to ascertain how the child's best interests are served. These decisions require the balancing of many varied considerations that cannot be deduced according to a formula and will ultimately involve a subjective judgement. It should also be noted that some decisions may be neither right nor wrong, and that reasonable people may reach different conclusions.

Quality of life

"Quality of life" is a term often used, but unfortunately it can be open to interpretation, or be ambiguous. Sometimes it is even confused or used interchangeably with the more legally and ethically acceptable term "best interests".

Quality of life is a wholly subjective concept and refers to the way life is experienced by the patient – what life is like for them, from their own perspective. This makes assessing the quality of life of a child quite difficult, especially if the child is too young to be able to describe his or her own experiences to others, or if an older child, due to illness or injury, is unable to communicate their thoughts and experiences. Rather than being about what activities the child can perform, or what abilities they have, quality of life refers more to what the child's life is like to them - what is like for them as an individual to have those particular capacities and experiences.

There must also be a positive effort to avoid projecting your own views about quality of a life onto the child. It is vital to remember when trying to assess a child's quality of life that you are trying to see the world through that child's eyes, not your own. The key question is "how does life feel for this child?" not "How would I feel if I were this child?" This is because the way we experience life, as happy or sad, good or bad, depends on our thoughts, feelings, desires, expectations and interests, as much as on our physical condition. This is particularly important when considering a child with a disability. There is an important difference between the experience of a child who has always had a disability, such as quadriplegia, and a child who was previously well and is now experiencing the loss of abilities that he or she once had, perhaps through a trauma. Parents are usually the best source of understanding what a child's life is like for that child, since they know the child best. But they are not infallible – parents may see what they want to see, fail to see what is unpleasant, or misinterpret signs of distress, all without realising it. Parents may also "read into" treatment options, such as withholding futile interventions, and wrongly conclude that the health care team is neglecting their child or wanting to unblock a bed. Nevertheless, parents' views must always be sought and careful attention paid to the way discussions occur about their child's quality of life in the context of treatment options available.

Some commentators have explored this notion further and refer to a "negative versus zero quality of life".¹² In other words, unpleasant experiences versus *no* experiences in

¹² Gillam, L. "More information on ethics and end-of-life decision-making". Royal Children's Hospital, Murdoch Children's Research Institute and University of Melbourne.
<http://www.rch.org.au/emplibrary/genmed/WebPageEthicsNotes.pdf> [accessed 5/3/2011]

the context of end-of-life decision-making. According to Gillam (undated), it is not uncommon to hear someone describe a child as having “no quality of life” or “low quality of life”. Unfortunately, these sorts of terms are ambiguous and sit between two very different concepts. One is “negative” or “bad” quality of life, where a child has only bad experiences, such as physical suffering and fear, or has a lot of bad experiences and few good ones, so that there are not enough good experiences (pleasure, happiness) to outweigh the bad ones. The other is “zero quality of life”, which strictly speaking means no quality of life at all – that is no experiences at all, either good or bad (for example, a child in a coma or with irreversible critical brain damage). This distinction is important from an ethical perspective. Prolonging the life of a child who has negative quality of life is causing harm to that child, because the child is suffering. But prolonging the life of a child with zero quality of life is not causing harm to the child, because the child is not capable of experiencing suffering. According to this argument, there may be other good ethical reasons not to prolong the life of a child with zero quality of life, but avoiding doing harm to child is not one of them.

Respect for the child’s developing autonomy

In order to act autonomously, one must act with intention and understanding and without controlling influences and the individual must demonstrate an understanding of their situation and the implications of their decisions. In the medical context, respect for autonomy involves not only allowing a patient to make informed choices regarding their care but facilitation of this process by ensuring they are well-informed and free of conditions such as fear, pain and depression which may compromise their capacity to make truly autonomous decisions. Decisions must also be able to be communicated in some way. Children represent a continuum in this regard; from the non-verbal infant to the adolescent striving for self determination. A child’s ability to make informed choices depends not only on their developmental level but on their life experience. For example, an eight year old child with a chronic illness may through their own experiences and those of their fellow patients be better positioned to participate in decision-making than an older child with no previous medical history.

Children may be able to make some decisions about their medical care even where major decisions are made by others. They may for example, make choices regarding pain control and venipuncture sites. Empowering children in this way gives them a sense of control which impacts more positively on their experience of care. Furthermore, even when a child is not deemed sufficiently competent to act autonomously, their preferences and insights may guide decision making by others and should be sought actively.

Children progress through varying degrees of competence as they grow, mature and acquire life experience. Their involvement in decision-making is subject to their level of competence and this must be judged on an individual basis (see Competence). Age is not necessarily a good measure of capacity although an arbitrary distinction is drawn for legal purposes.

Decision-making in the paediatric end-of-life care setting requires:

- The ability to understand one’s illness in physiological terms and to conceptualise death as an irreversible phenomenon;
- The capacity to reason and consider future implications (formal operations stage of cognitive development); and
- The ability to act autonomously and not acquiesce to the authority of doctors and parents

Respect for parents as decision-makers

In recent decades, many legal disputes and ethical debates about care for infants and children have involved decisions to start or stop medical interventions. Other disputes focus on the limits of parents' authority to decide about their child's care and on whether and to what extent quality-of-life and financial considerations should influence decisions about life-sustaining treatments. Much of the initial discussion of some of these issues, for example, withholding and withdrawing life-support technologies, occurred in the 1970s and 1980s and predated the increased attention to the techniques and benefits of palliative care. Again, the issues are not necessarily unique to children but tend to be more emotionally charged and difficult for all involved.

When providing information, the clinical issues should be explained in a way that the parents can understand. When difficult or potentially distressing issues about the child's prognosis and care arise, this should be approached with tact and sensitivity. It is also important not to make generalisations or assumptions about the parent's ability to cope with their dying child. Regular "check-ins" should be part of the care-giving and arrangements made for family support to be sought from the appropriate areas if the parents are unable to cope.

Well-being of the child's family

In general, parents have the legal right to make decisions about medical care for their child. This parental authority is occasionally challenged, usually when parents refuse treatment recommended by their child's physician. In addition, adolescents have sometimes sought control over crucial decisions about their future, often in situations involving reproduction but sometimes involving care for far advanced illness. That parents have the legal right to make decisions does not and should not mean that parents and clinicians should simply exclude children from discussions and decisions about their care. Failing to provide children with information and the opportunity to discuss their fears, concerns, and preferences can isolate them and add to their anxiety and other distress.

It is recommended that children and adolescents be informed and involved in decision-making consistent with their condition, maturity, and preferences and with sensitivity to the family's culture and values. Involving the child and trying to see care through the child's eyes is also an element of child- and family-centred care. Care must, however, be taken not to give the false impression that parents will never override their child's expressed wishes. Deeply held cultural values may lead parents to reject proposals to involve the child or even provide the child with information about his or her condition. Clinicians may respect these values but still be dismayed. Although it is important to understand the ethical and legal context for decision-making, most disagreements about care are resolved informally through discussion and reflection.

Fair and equitable resource allocation

All health professionals not only have an ethical duty to make the best use of available resources. They also have an explicit responsibility to provide equity of access to the health care system. However, making the best possible use of resources inevitably means that some patients, whose lives might potentially be prolonged, may not receive

all possible life-sustaining treatment. Decisions around life-sustaining measures must represent an appropriate balance between the clinical and resource needs of different patients, while having regard to the availability of medical treatments, particularly in acute settings.

Increasing levels of technology not only present ethical dilemmas about assessing when treatment ceases to benefit the patient, but also raise the issue of cost when the decision is made to withhold or withdraw a particular treatment. Where funds are limited, individual facilities, medical officers and patients all compete for sometimes scarce resources.

Particular difficulties could arise if, for example, patients or their families request life-prolonging treatment to be continued for as long as technically possible, even though there is no hope of recovery. Complying with such requests could well be at the expense of other patients who have a reasonable chance of recovery if treatment is provided.

Some of this decision-making also takes into account the likelihood of prolonging life leading to a significant recovery for one patient against the likelihood of merely delaying death for a short period of time or prolonging the dying process for another. Although it is highly unlikely the courts would expect all possible treatment to be given to prolong a life irrespective of costs or the impact on other patients, the onus is on the most senior medical officer of the treating team to clearly articulate the decision-making that led to the final outcome. Meticulous record-keeping is crucial in these circumstances.

There are no simple solutions to balance the variables in providing fair and equitable access to health care while meeting prudent efficiency standards. Ideally, decisions about access to treatments should be made on the basis of an agreed local or national policy that takes account of the human rights implications. Decisions made on a case-by-case basis, without reference to agreed policy, risk introducing elements of unfair discrimination or failure to consider properly the patient's legal rights. If resource constraints are a factor, you must:

1. Provide the best service possible within the resources available;
2. Be familiar with any local and national policies that set out agreed criteria for access to the particular treatment;
3. Make sure that decisions about prioritising patients are fair and based on clinical need and the patient's capacity to benefit, and not simply on grounds of age, race, social status or other factors that may introduce discriminatory access to care; and
4. Be open and honest with the patient (if they have capacity), or those close to them, and the rest of the healthcare team about the decision-making process and the criteria for prioritising patients in individual cases.

Although the courts have given little guidance, using resource allocation as an excuse for withholding or withdrawing life-sustaining measures would most likely be challenged legally, and, arguably, serious charges could be faced under a range of different legislation. A number of legal cases have examined the provision of medical treatment on the grounds of such things as futility (most notably the *Bland* case). However, the legal implications of using resource allocation in defence of a decision to withdraw a life sustaining measure is yet to be tested.

Decision-making regarding life-sustaining measures must be based on the child's best interests, underpinned by good medical practice. While it is acknowledged that balancing competing interests is profoundly complex, the extent of the duty of care for the entire health care team would be judged on a case-by-case basis if the decisions were to be

tested by the court. Concluding resources are too costly to keep the patient alive simply because the treatment is “futile” treads a dangerous legal path and is fraught with ambiguity and both clinical and moral complexity. Particular care needs to be taken to ensure that all decisions have been carefully considered, based on an child’s care needs, and not made on the basis of unjustifiable discrimination (both of the child as an individual and of the child compared to others).

Decisions regarding life-sustaining measures must always be well-supported by clinical evidence, second or expert opinions, and by reference to Queensland Health documents and other relevant national guidelines. Should there be any doubts about a particular course of action expressed by any member of the health care team, or expressed by a member of the child’s family, these concerns should be discussed with senior clinical and managerial colleagues. All records should be kept in the patient’s file and later referred to the hospital area ethics committee, if this is available.

Resources for gravely ill or irreversibly and severely brain-damaged patients who will never recover cannot be allocated to treat other patients, and this exceptionally difficult ethical dilemma will necessarily comprise some decision-making about life-sustaining measures. For example, does a patient who suffered severe trauma at a young age and now lives in a disability long-term facility meet this criteria despite maintaining an acceptable base-line functioning? The British Medical Association have also addressed some of these issues in their guidance, but do not provide definitive advice, ultimately leaving the final decisions to the medical officer in charge, supported by the health care team. However, it is very concerning that the reality is, that cost factors probably have a disproportionate influence on decision-making for this very vulnerable patient group and it is also concerning that the lack of a clear societal consensus on this most vexed area may unfairly leave medical officers open to criticism.

Health professionals should be careful never use lack of current or indeed future resources to deny treatment for any patient. To do so establishes a conflict since, in essence, the choice to treat the patient (or not) is being compared with the treatment for another (future) patient whose condition is unknown. Each patient should be assessed on a case by case basis, taking all the clinical factors into consideration. In the case where two patients share the need for the same limited resource, which is adequate for both, “the patient with the greater clinical need should have the first access. This is the essence of triage.”¹³

It is important to acknowledge that medical officers are well placed to make informed decisions about patient care that can include economically smart choices, as long as patient care does not suffer. Regrettably, a common misconception held by family regarding withdrawal of medical treatment is that medical staff do so to ‘free the bed’ for someone else. Doctors are advocates for their patients, and are bound to act in their best interests, both by law and by adhering to the standards of good medical practice. Their primary duty is always to the patient they are treating, and the care of that patient will not be compromised for the care of another potential patient.

Moral questions

While the two terms are often used interchangeably, there is a distinction to be made between morals and ethics. For the purpose of this guideline, the following definitions are offered:

¹³ Kerridge, I., Lowe, M. & McPhee, J. (2005). p. 559.

- Morals, such as a person's moral principles and convictions, are qualities that determine a person's character. Understanding the difference between, and notions of, right and wrong come from personal convictions - a person's morals. Moral principles are normative in nature; that is, they are the basis from which an imperative to act originate.
- Ethics relate to personal, institutional and broader social regulations and systems. To act ethically is to regulate one's (and/or others') behaviours so they are in accordance with a moral or set of morals. Ethics is a systematic approach to morality, based on reason and moral justification.

There are two significant and distinct approaches to moral philosophy - objective and subjective. Objective approaches to moral philosophy seek to determine universal principles applicable to all, whereas subjective approaches tend to hold that ethical behaviour is not universal in nature and is determined by context and consequence. Also for the purpose of these guidelines, while each patient's clinical treatment will be determined on a case-by-case basis, the four Governing Principles embody moral principles that are to be applied to all patients.

The types of moral questions raised in this section are directed in the context of treatment and care of children who may be competent for making (and justifying) their decision-making processes for life-sustaining measures and also parents or those with parental authority who make decisions on behalf of a child is not competent to consent to treatment. Therefore health care professionals can refer to this section to test their own values about what they consider to be right and wrong.

Other interested parties may find this guidance useful if they are faced with these decisions at some future time in their lives. Answers to these moral questions are, quite obviously, subjective, and as such cannot realistically be determined on a yes or no basis. However, they can provide a process for ethical deliberation for decision-making in this difficult area and will either affirm personal values or challenge them. In exploring the moral considerations inherent in making decisions about the withholding and withdrawing of life-sustaining measures, it is useful to consider the four bioethical principles:

Autonomy – respect for the individual and their ability to make decisions about their own health and future. Actions that enhance autonomy are thought of as desirable, and actions that override an individual and their autonomy are undesirable.

Beneficence – actions intended to benefit the patient or others.

Non-maleficence – actions intended not to harm or bring harm to the patient and others.

Distributive Justice – being fair or just to the wider community in terms of the consequences of an action.

To recap, the following moral questions will be briefly discussed:

- What does it mean to respect human life?
- What is benefit?
- How can risk of harm be minimised?
- What is futility?
- What is the doctrine of “double-effect”?
- How do I respond to requests for euthanasia?
- What is the meaning and value of death?

- Can I abstain from treating on the basis of conscience?

What does it mean to respect human life?

Doctors have an ethical obligation to show respect for human life; protect the health of their patients; and to make their patients' best interests their first concern. This means offering those treatments where the possible benefits outweigh any burdens or risks associated with the treatment, and avoiding those treatments where there is no net benefit to the patient. Benefits and burdens for the patient are not always limited to purely medical considerations, and doctors should be careful, particularly when dealing with patients who cannot make decisions for themselves, to take account of all the other factors relevant to the circumstances of the particular patient. It may be very difficult to arrive at a view about the preferences of patients who cannot decide for themselves, and doctors must not simply substitute their own values or those of the people consulted.

Prolonging life will usually be in the best interests of a patient, provided that the treatment is not considered to be excessively burdensome or disproportionate in relation to the expected benefits. Not continuing or not starting a potentially life-prolonging treatment is in the best interests of a patient when it would provide no net benefit to the patient. In cases of acute critical illness where the outcome of treatment is unclear, as for some patients who require intensive care, survival from the acute crisis would be regarded as being in the patient's best interests. Life has a natural end, and doctors and others caring for a patient need to recognise that the point may come in the progression of a patient's condition where death is drawing near. In these circumstances doctors should not strive to prolong the dying process with no regard to the patient's wishes, where known, or an up to date assessment of the benefits and burdens of treatment or non-treatment.

What is benefit?

Our health system and its health professionals have a general duty to provide treatment which benefits all patients; the bioethical principle of beneficence being one of the four cornerstones of modern health care. Benefit, in this context, means an advantage or net gain for the child. Because end-of-life decision-making for those patients under the age of 18 years involves ensuring all decision-making is in their best interests, the concept of benefit becomes very important to be able to articulate clinically and ethically. Benefit can be physiological or it can also be other factors important to the patient, such as quality of life. A therapeutic benefit occurs when a medical treatment or procedure confers some sort of symptomatic relief for the patient or improves the patient's condition or prognosis in a real and meaningful way. This treatment is justified as it provides a real benefit.

Health professionals also have responsibilities toward society in addition to the responsibilities they have to individual patients. Clinicians are employed by society to provide medical care. The burden of prolonging life in the most extreme cases where there is profound morbidity and no reasonable prospect of recovery should weigh on the side of palliation and supportive therapies rather than finding cures through active and invasive treatments. Arguably, in these cases, there is little or no benefit in subjecting a dying child to an endless regime of tests and therapies that are potentially futile and have no chance of restoring their health. Applying life-sustaining measures to prolong life in these circumstances may be causing more harm to the patient than benefit, particularly if pain is involved. This is where the health care team must carefully weigh up and consider all factors to ensure the child's best interests are protected and upheld.

Another key community expectation of our health system is that treatment benefits will outweigh the harms. In decision-making about withholding and withdrawing life sustaining measures, a similar test applies. It is a tenuous moral and ethical balancing act to

determine what benefits a patient might receive against harm done to them. Open and honest communication with the child and their family can assist in the decision-making process.

When contemplating how the child may benefit from certain forms of treatment, unilateral decisions about withholding or withdrawing a life-sustaining measure must never be made. *Gillick*-competent children are in the best position to judge what represents an acceptable level of burden or risk for them, and their wishes must be respected even if this results in perceived harm to them. Provided these risks are explained in a way suitable to the child's cognitive development and level of maturity and discussed with the child's parents, this may provide beneficial planning for future care and subsequent clinical direction. This important principle underpins the concept of patient autonomy.

In circumstances where children are not competent nor have capacity to contribute to future health care decisions on their own behalf, they cannot be involved in assessing whether benefit is achieved. This duty falls to the child's parents to interpret wishes expressed by the child in some way. For example, if an adolescent patient is known to have the view that there is no intrinsic value in prolonging life at any cost, life-sustaining measures would, arguably, provide no benefit to that individual. This view must be taken into consideration in the weighing up of any potential benefits of future treatment.

The ability to apply reason in these instances hinge on the child's level of maturity, intelligence and awareness. For example, important factors in assessing a child's awareness is demonstrated by the ways in which they:

- interact with others
- are aware of their own existence and abilities to take pleasure in the fact of that existence
- have the ability to achieve some purposeful or self-directed action or to achieve some important personal goal.

Should treatment or health care be able to recover or maintain any of these abilities, this likely indicates some benefit to the patient. Benefits are increased if improvements are in the context of the patient's known wishes and values about quality of their own life. Factors that should be considered when making decisions about life-sustaining medical treatment for a patient under the age of 18 years includes:

- The chance the therapy will succeed
- The risks involved with treatment and non-treatment
- The degree to which the therapy if successful will extend life
- The pain and discomfort associated with the therapy
- The anticipated quality of life with and without treatment

As previously stated, the benefits of a treatment that may prolong life, improve a child's condition or manage their symptoms must be weighed against the burdens and risks for that child, before you can reach a view about its overall benefit. For example, it may be of no overall benefit to provide potentially life-prolonging but burdensome treatment in the last days of a child's life when the focus of care is changing from active treatment to managing the child's symptoms and keeping them comfortable. The benefits, burdens and risks associated with a treatment are not always limited to clinical considerations, and you should be careful to take account of the other factors relevant to the circumstances of the child and their family circumstances.

Gillick-competent children who have capacity to make health care decisions on their own behalf will reach their own view about what personal factors they wish to consider and the weight they wish to attach to these alongside the clinical considerations.

In the case of children who are not competent or who lack capacity to contribute to decisions about their health care, their parent/s will be responsible for making these judgements in consultation with the health care team.

How can risk of harm be minimised?

The concept of non-maleficence is embodied by the phrase, “first, do no harm”. Many consider that should be the main or primary consideration in health care (hence *first*): that is, it is more important not to harm your patient, than to do them good.

Just how the idea of harm can be determined is another key moral question. There is always the presumption that medical treatment provides benefit to a patient. However, in terms of end-of-life care, the child may be harmed by both the withdrawal of treatment too quickly and by prolonging the treatment beyond the point where it is able to benefit him or her.

It is also the case that children who are competent to contribute to their own health care decisions may also be harmed by treatment being provided or withheld or withdrawn against their wishes. For example, where *Gillick*-competent children are known to have refused treatment, these instructions must be examined in light of all the factors involved, but the treatment refusal must ultimately be respected. Treating any patient against their stated wishes is, in itself, a form of harm and may even be viewed by the courts as a form of assault. In these difficult cases, the focus must be kept on the child and his or her best interests.

There may be a disparity in perspectives between harm and benefit in many medical treatments, for example, CPR, artificial nutrition and blood transfusions. In the treatment of patients under the age of 18 years, blood transfusions may be given, despite the parents of the child refusing to consent on the grounds of religious objection. Under similar principles that determine what harm could be caused to children by medical treatment, doctors are under no obligation to provide medical treatment that are not in the best interests of the child, in other words, treatment that would confer no benefit and cause harm.

Harm may also be caused by reluctance and prevaricating about withholding or withdrawing life sustaining measures. Failing to make difficult decisions in a timely manner and thereby subjecting an incompetent child to undignified invasive treatment would also qualify as harm. In these situations, families would also face significant and distressing anguish as their child suffers longer than is absolutely necessary.

End-of-life decision-making can also be a time-consuming process. Quite often more time is needed to assess the best interests of the patient, particularly where there are doubts, disputes or competing interests. In these instances, consideration should be given to a trial of treatment which allows time for the child to stabilise and provides more information about the likelihood and extent of any improvement. Families may also benefit from this period as they come to terms with the condition and likely prognosis of their loved one. Failing to give dying children and their families this opportunity for improvement where there is even the slightest chance it may be successful could also constitute harm.

Reducing the risk of causing harm in end of life care should involve careful consideration of the patient’s medical condition and likely prognosis. This information should be

communicated to patients and their families as soon as possible to avoid crisis-driven decision-making.

What is futility?

There is no universal consensus on what the term ‘futile treatment’ means. It is difficult to define and an elusive task to uncover a manual or a set of guidelines that determines whether or not treatment is futile. The issue is fraught with ethical, medical and legal challenges. There is a heavy presumption in favour of administering life-sustaining medical treatment to a patient where that treatment provides a net benefit to the patient. Modern technology and medical advancements have enabled health care to treat disease and sustain life by artificial means when organ or system failure would otherwise naturally result in death.¹⁴

These technological and medical advances have brought with them new ethical questions. For example, is it the case that if a medical intervention is found to be technically possible in one case, it should be applied or attempted in all similar cases? Is it the case that everything that can possibly be done should be done? These are not questions which can be easily answered. Everyone, doctors most of all, know there comes a point when a patient is overcome by their disease and medicine is powerless to intervene. The difficulty lies in defining this point with the precision, accuracy and ethical cogency required to guide clinical practice and gain community acceptance.

One simple definition of futile medical treatment is: *treatment that gives no, or an extremely small, chance of meaningful prolongation of survival and, at best, can only briefly delay the inevitable death of the patient.*¹⁵ The word ‘meaningful’ in this context is usually interpreted in light of the values, beliefs and quality of life factors that are important to an individual. A meaningful recovery generally affords a level of quality of life that the patient deems acceptable, or which the average, reasonable person deems acceptable.

While futile medical treatment is a relative concept, this becomes more difficult to assess in children, even though the same principles apply to adults. Whether or not something is futile can only be judged with reference to its goal. So when questions arise about whether medical treatment is futile, the key issue to consider is the goal of treatment. Doctors and parents may have different views about what the goals are, and so different views about whether or not a particular treatment is futile. (Of course, the same differences can exist between individual clinicians). Children may also be able to communicate in some way about their preferences, or non-preferences for certain therapies thus placing more “weight” to the decision-making.

For example, parents may see the goal as keeping their child alive for as long as possible, even if the child has severe and irreversible brain damage and permanent loss of consciousness. The treating doctor may see the goal of care as improving the child’s quality of life, and producing some improvement in their condition and keeping them free from pain and any distress. In this situation, parents would see continued ventilation as an effective treatment, because it would succeed in keeping the child alive. Doctors may see continued ventilation as futile, because it would not be able to achieve the goal of improving the child’s medical condition or quality of life. The issue here is not about whether ventilation is futile, but rather about what goal is appropriate, alternatively what outcome is worth aiming for. This is a difference in values, not a difference in facts, and is

¹⁴ M. Heaney, C. Foot, W. Freeman, J. Fraser. (2007), p. 278

¹⁵ Murphy, B. (2008). p. 418.

not easily resolvable. Nevertheless, progress cannot be made until the goals of the relevant parties have been identified.

Ultimately, judgements on whether or not a medical treatment is potentially futile are going to be at least partially subjective. Recent procedural approaches to the determination of futility accept that it is not possible to be wholly objective on this issue, and therefore processes (some of them statutory) based on fairness and the child's best interests at the end of life should prevail.

Futile medical treatment and euthanasia – the difference

Despite the complexity in defining 'futile treatment', the literature on the subject makes clear between decision-making around potentially futile medical treatment and euthanasia. Withholding or withdrawing life-sustaining futile medical treatment is not done with the intention of killing the patient. It is distinguished from euthanasia because its primary goal is not to bring about the death of the patient.

Withdrawing life-prolonging medical treatment helps the already dying patient to achieve a peaceful and dignified death, so that suffering and death is not unnecessarily prolonged as a result of medical intervention. Once the treatment focus shifts to palliative care, the primary goal is to relieve uncomfortable or unwanted symptoms rather than to cure the disease or condition. The paediatrician or medical officer in charge of providing pain relief must do so with the primary purpose of obtaining symptomatic control of the child's pain, discomfort or distress, and not to cause or hasten the child's death; even though this may be one of the effects of administering such pain relief. This is known as the 'principle of double-effect' (see below), and is readily distinguished from euthanasia or assisted suicide.

Futile medical treatment and the law generally

There are well established common law principles that clinicians are under no moral or legal obligation to attempt medical treatment that could cause harm or would provide no benefit to a patient. The Court of Appeal recently concluded that "...ultimately, however, a patient cannot demand that a doctor administer a treatment which the doctor considers is adverse to the patient's clinical needs."¹⁶ Therefore, children competent to consent to decisions about their health care, or those holding parental authority to act on behalf of their child, cannot demand treatment that clinicians believe to be futile.¹⁷ This includes all life-sustaining measures, such as cardiopulmonary resuscitation (CPR), dialysis, ventilation, and in some circumstances, even enteral or intravenous nutrition. Potentially futile medical treatment goes against a patient's best interests and therefore, at common law, need not be offered.

Potentially futile medical treatment is also associated with the test of best interests. If the medical treatment, on the balance of probabilities, will offer no benefits and cause the patient harm, the treatment may be withheld or withdrawn. Although the decision to withhold or withdraw life-prolonging medical treatment is ultimately a clinical decision, while the patient's family can offer important insights into the patient's beliefs and views regarding end of life decisions, the clinician's duty of care is always to the child and their best interests, not those of their family.

There is plenty of case law where families have challenged the clinical assessment that providing further treatment to their loved one is deemed to be futile.¹⁸ Courts are not bound by the views of the medical profession and will reach an independent assessment

¹⁶ *R (on the application of Burke) v General Medical Council* [2006] QB 273, 301.

¹⁷ Skene L. (2004).p. 307.

¹⁸ *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549, 554

of what the patient's best interests require.¹⁹ However, the courts have also said, in the context of futility, that the "decision as to appropriate treatment ... is principally a matter for the expertise of professional medical practitioners".²⁰ If a court concludes that medical treatment is futile and therefore not in a patient's best interests, that treatment need not be continued.

Because patients under the age of 18 years are not subject to the guardianship legislation, but rather under common law, the difficulties in the relationship between both jurisdictions are not relevant. In some ways this makes the decision-making more straight forward. For children, potentially futile medical treatment must be linked to the test of best interests for the child. If the doctor in charge of the child's care believes that further invasive medical treatment is not in the child's best interests, is potentially harmful and will offer the child no benefits (futile), the treatment need not be offered nor provided. However it should be noted here that where the parents disagree with this clinical decision, it would be prudent to resolve the differences before an application is made to the courts to decide. [See section on Legal Framework]

What is the doctrine of double-effect?

Once a decision has been made to withhold or withdraw life-sustaining medical treatment, the focus must turn to comfort measures and a transition to palliative care for the child. The doctrine of double effect, which has its origins in the teachings of Thomas Aquinas, is widely accepted in both ethics and law. This allows treatment to be given to alleviate painful or distressing symptoms even if it is foreseen that the treatment may hasten death. An example would be the use of opiates in palliation of distress, although there is good evidence that they are regularly given in doses that far exceed those required purely for palliation.²¹ There are classically four conditions which an act must fulfil to satisfy the doctrine of double effect:²²

1. The act itself must be morally good or at least indifferent.
2. The intention must be to cause the good effect (e.g. patient comfort). The bad effect (e.g. hastening of death) can be foreseen, but there must be no other way to achieve the good effect.
3. The bad effect must not be the means of producing the good effect – it is not permissible to use a bad means to a good end.
4. The good effect must be sufficiently desirable to compensate for the allowing of the bad effect.

Clinicians' attitudes and practices related to the use of life-sustaining medical interventions may be influenced by a number of factors including their cultural or religious values and their emotional response to a child's grave illness or injury. Other factors include ignorance or misunderstanding of the evidence about the benefits and burdens of specific interventions.

¹⁹ White, B. & Willmott, L. (2005). p. 70.

²⁰ *Isaac Messiha (by his tutor Magdy Messiha) v South East Health* [2004] cited in White, B. & Willmott, L. (2005), p. 70.

²¹ Sprung C, Ledoux D, Bulow H-H et al. Relieving suffering or intentionally hastening death: where do you draw the line? *Crit Care Med* 2008; 36: 8-13.

²² Wellesley H, Jenkins IA (2009). Withholding and withdrawing life-sustaining treatment in children. *Pediatric Anaesthesia* 2009; 19:972-978.

How should I respond to requests for euthanasia?

In Queensland, euthanasia is unlawful to the extent that it constitutes killing under the *Queensland Criminal Code 1899*.²³ Euthanasia and assisted suicide both involve deliberate acts or omissions that are undertaken with the deliberate intention of ending a person's life and are inconsistent with the duty of care of a medical practitioner or other medical professionals. **Both euthanasia and assisted suicide are criminal offences and are not endorsed by this document, nor by Queensland Health.**

Euthanasia itself has many definitions. The most common definition is: 'Any action or omission intended to end the life of a patient on the grounds that his or her life is not worth living.' Some look toward a 'modern' definition which states that euthanasia is: 'A good death brought about by a medical officer providing drugs or an injection to bring a peaceful end to the dying process'. Three classes of euthanasia can be identified: passive euthanasia, physician-assisted suicide and active euthanasia, although not all groups would acknowledge them as valid terms.²⁴

Proponents of euthanasia believe it is the compassionate choice, and supported by the same constitutional safeguards that guarantee such rights as marriage, procreation and the refusal or termination of life-saving medical treatment. Proponents feel the language of the often-cited Hippocratic Oath negates the reality of terminal disease, and believe that terminally ill people should have the right to end their pain and suffering with a quick, dignified death.

Opponents of euthanasia use the 'slippery slope' argument and see little difference between it and murder, and challenge that any test to differentiate between voluntary and non-voluntary cases will ultimately fail. They also cite the Hippocratic Oath, arguing that medical officers have a responsibility and a sworn duty to keep their patients alive. Many opponents believe that legalising euthanasia will unfairly target the poor and disabled, groups with little access to advanced, possibly life-saving medical care.

Most discussion in paediatric palliative care centres around passive non-voluntary euthanasia or 'selective non-treatment' in which 'death is deliberately produced by withholding or withdrawing the ordinary means of nutrition or treatment of the subject's condition'. It is important to draw a distinction here between good medical practice and euthanasia. Good medical practice involves making a judgement based on whether a given intervention is in the best interests of the patient.

The medical officer may predict that death will result but this is not the intention. Euthanasia (be it passive or active) centres on the deliberate intention to bring about the death of the patient. Health professionals do not wish to actively end patients' lives. On the other hand, they do not wish to contribute to suffering by continuing therapies which are unlikely to benefit the patient, cause them harm, and are not in their best interests. The Royal College of Paediatrics and Child Health draws a clear distinction between palliative care and euthanasia: "When a dying patient is receiving palliative care, the underlying cause of death is the disease process. In euthanasia, the cause of death is the intended lethal action".²⁵

A practical issue which often arises in the context of palliative care is concern over whether the management of symptoms with opioids hastens death. There is currently no evidence that death is hastened when opioids and anxiolytic agents are used correctly

²³ *Queensland Criminal Code 1899*, s. 284 & Chapter 28.

²⁴ "Euthanasia Special Report," www.bbc.co.uk July 1, 1999

²⁵ Royal College of Paediatrics and Child Health. *Withholding or Withdrawing Life Saving Treatment in Children*. London, 1997.

(that is titrated upward according to patient tolerance and symptom severity) “the knowledge and skills built up over some 30 years of palliative care practice have shown that opioids and sedative drugs can be used quite safely for symptom control without bringing causation into question if the parameters of accepted practice are followed.”²⁶

What is the meaning and value of death?

Death is the only great certainty. The subject of powerful social and religious symbolism, it continues to be contemplated by philosophers, probed by biologists, and its reality dealt with families and clinicians on a daily basis. Arguably, nowhere is this more acutely questioned than in a paediatric ICU. Children are not meant to die prematurely and parents, supported by society invest love, encouragement and care to ensure this does not happen.

Our cultural and individual orientations toward death are intimately interwoven. It is well documented that in Western culture, the attitude towards death is often denial (or perhaps more accurately, suppression). Death is defined in Queensland legislation as the irreversible cessation of circulation of blood in the body of the person, or the irreversible cessation of all function of the brain of the person.²⁷ But a discussion about social and cultural meaning of death in any society goes much further than a clinical determination that death is simply the cessation of life.

More concerning for some researchers²⁸ is the absence of an agreement on the definition of dying. The lack of a clear definition means that, for the purposes of research, we can never be certain about who to include in the population or cultural groups and who to exclude. Research into end-of-life issues becomes, by its very nature, is subjective because of this lack of conceptual clarity.

In short, I view the absence of conceptual and operational congruity regarding definitions of ‘dying’ and/or ‘terminally ill’ as the most important issue facing end-of-life research. I cannot see the field breaking new ground or ‘reaching the next level’ without resolving this issue.²⁹

Leaving the definition of ‘dying’ aside, it can be confidently stated that death is not as predictable as it was, for example, 50 years ago. This is for many reasons, most significantly the successful combination of medical innovation and modern societies’ preoccupation with keeping its population safe and healthy. This has caused our life expectancy to increase over the last century. For example, a girl baby born at the time of Federation lived 23 years less than a girl baby born in the new Millennium is expected to.³⁰

Unfortunately, in many cases, this increase in lifespan and decrease in mortality rates have not been matched by an extension of good health. The years we have gained are often spent with disability, disease, dementia and aggressive medical interventions. Before life-sustaining measures such as artificial hydration, nasogastric feeding and respirators, no patient continued for long in deep coma. With the aid of modern medicine, some patients with severe loss of brain function can be kept from a rapid death. Many, however, become permanently and totally unresponsive. These patients can be seen breathing, their heart beating, and may even be observed to have different facial

²⁶ Ashby M. On causing death. *Med J Aust* 2001; 175: 517-8.

²⁷ *The Transplantation & Anatomy Act 1979*, s. 45(1)

²⁸ George, L.K (2002), p. 87

²⁹ George, L.K (2002), p. 87

³⁰ ABS statistics, 1301.0 - Year Book Australia, 2001; —A Century of Population Change in Australia

expressions, but are in a comatose state from which they are not likely to recover. This can also be applied to extremely preterm infants or neonates with severe congenital abnormalities; while the heart still beats there is hope that life will prevail.

Such artificially maintained bodies present ethical dilemmas, for which the application of traditional means of determining death is neither clear nor fully satisfactory. This illustrates why decision-making about withholding and withdrawing life-sustaining measures has become so medically complex and ethically challenging. And it is not just the clinical side of death that is challenging for the health care team. Awareness of death confronts us with questions that go to the very nature of existence.

Palliative care professionals, in particular, have increasing responsibilities in caring for growing numbers who are dying and comforting the bereaved family and friends. However, it should not be left to the sole responsibility of palliative care teams to address end of life decision-making. Irrespective of personal attitudes to the meaning and value of death, it should be that all the health care teams leading up to the time of palliation will respect all patient's wishes and respond to the ultimate problem of death in a thoughtful and caring manner by acknowledging rituals that reflect and advance values of human worth, dignity and enduring connection.

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

Under a range of legislative principles, even if a patient or family requests it, individual health professionals are not obliged to give treatment which, in their view, is not in the best interests of the patient and would contravene the standards of good medical practice. Therefore, in very limited circumstances, medical officers are excused from providing care to a patient that goes against their conscience or clinical judgement.

In the case where health professionals have a conflict of interest or object on the grounds of conscience, this must be declared as early as possible to ensure the patient receives appropriate hand-over to another medical officer and/or health care team. Where a medical officer disagrees with the child or his/her parents, and this cannot be resolved, there are legislative procedures that will more than likely be settled by the courts.

You can object to providing treatment to a patient on the grounds of conscience if your religious, moral or other personal beliefs about decisions concerning life-sustaining medical treatment lead you to object to comply with:

1. a parent's decision to refuse treatment for their child; or
2. a decision that providing such treatment is not of overall benefit to a patient who lacks capacity to decide.

However, you must not do so without first ensuring that arrangements have been made for another doctor to take over your role. It is not acceptable to withdraw from a patient's care if this would leave the patient or colleagues with nowhere to turn.

Where a decision to withhold or withdraw life-prolonging treatment has been made by a competent adult patient, or made by the senior clinician responsible for the care of a patient who lacks capacity to decide (following discussions with those close to the patient and the health care team) doctors who have a conscientious objection to the decision may withdraw from the care of that patient. In doing so they must ensure, without delay, that arrangements have been made for another suitably qualified colleague to take over their role, so that the patient's care does not suffer. Junior doctors in this position must make their conscientious objection known to the doctor responsible for the patient's care

who should then ensure that arrangements are made for another colleague to take over from the junior doctor.

COMMUNICATION

Introduction

Communication is the foundation of the therapeutic relationship; it is the basis of fiduciary and ethical obligations of physicians to patients and their families. Effective health care communication is an essential tool for accurate diagnosis and for the development of a successful treatment plan, correlating with improved patient knowledge, functional status adherence to the agreed-on treatment regimen, improved psychological and behavioral outcomes, and even reduced surgical morbidity. In the case of distressing news, skillful communication can enable a family to adapt better to a challenging situation, including a child's unanticipated impairments. Poor communication, on the other hand, can prompt lifelong anger and regret can result in compromised outcomes for the patient and family, and can have medicolegal consequences for the practitioner.³¹

Other commentators who explore various elements of communication in paediatrics have referred to the concept of "collaborative communication"³² as a key organising framework. According to Feudtner (2007), collaborative communication encapsulates both the exchange of information and the nature of the collaborative relationship between the persons who are communicating. Importantly, that it also recognises the essential reciprocity and dynamic synergy of this pair of concepts, whereby better communication enhances collaboration, and more skilful collaboration can improve communication. Feudtner (2007) identifies five important tasks to achieve collaborative communication:

1. Establishing a common goal or set of goals that guide collaborative efforts.
2. Exhibiting mutual respect and compassion for each participant.
3. Developing a sufficiently complete understanding of differing perspectives.
4. Assuring maximum clarity and correctness of what is communicated to each participant.
5. Managing intrapersonal and interpersonal processes that affect how information is received and processed.

Children have not always been consulted about their health concerns.³³ This has been largely attributed to the dearth of tools to clarify children's conceptualisation of health and illness, to assess their capacity for decision-making, to effectively share information with children, and to assess the outcome of shared decision making on the child patient.³⁴ According to the literature (Feudtner, 2007), children can be coached to effectively assume the role of a health partner, encouraged and even "coached" to be an effective advocate for his or own health. In the absence of children's input, it is difficult to understand the nature and severity of symptoms experienced, for example pain. It has

³¹ Levetown, M. (2008). Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information. *Pediatrics*: 121, 5. May 2008.

³² Feudtner, C. (2007). Collaborative communication in pediatric palliative care: a foundation for problem-solving and decision-making. *Pediatric Clinics of North America*. Vol 54. 583-607.

³³ Young B, Dixon-Woods M, Windridge KC, Heney D. Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents. *BMJ*. 2003;326(7384):305-309; Rushforth H. Practitioner review: communicating with hospitalised children: review and application of research pertaining to children's understanding of health and illness. *J Child Psychol Psychiatry*. 1999;40(5):683-691

³⁴ McCabe MA. Involving children and adolescents in medical decision-making: developmental and clinical considerations. *J Pediatr Psychol*. 1996;21(4):505-516

been reported that children as young as four years of age have used patient-controlled anaesthesia effectively.³⁵

In some cases, although this is becoming increasingly rare, parents mistakenly believe that not informing the child is best. Some professionals argue that paternalistic decisions (primarily on the part of the family) to withhold “harmful” information from the child can be justified.³⁶ This position is not supported in the literature that examines the child’s preference for information.³⁷ An interesting paper comes from Bluebond-Langner’s study of terminally ill children, which indicates that children as young as three years of age are aware of their diagnosis and prognosis without ever having been told by an adult.³⁸

³⁵ Dunbar PJ, Buckley P, Gavrin JR, Sanders JE, Chapman CR. Use of patient controlled analgesia for pain control for children receiving bone marrow transplantation. *J Pain Symptom Manage*. 1995;10(8):604–611

³⁶ Lantos JD. Should we always tell children the truth? *Perspect Biol Med*. 1996;40(1):78–92

³⁷ Waechter EH. Children’s awareness of fatal illness. *Am J Nurs*. 1971;71(6):1168–1172; Leikin S. A proposal concerning decisions to forgo lifesustaining treatment for young people. *J Pediatr*. 1989;115(1): 17–22; Van derFeen JR, Jellinek MS. Consultation to end-of-life treatment decisions in children. In: Steinberg MD, Youngner SJ, eds. *End-of-Life Decisions: A Psychosocial Perspective*. Washington, DC: American Psychiatric Press;1998:137–177; Gadow S. An ethical case for patient self-determination. *Semin Oncol Nurs*. 1989;5(2):99–101

³⁸ Bluebond-Langner M. *The Private Worlds of Dying Children*. Princeton, NJ: Princeton University Press; 1978

Children need to have usable information, to be given choices (including their desired level of involvement), and to be asked their opinion, even when their decision will not be determinative.³⁹ This is particularly the case for adolescents. If adolescents are to be given authority for their health care decisions, they must receive thorough, developmentally appropriate, understandable information,⁴⁰ to enable an understanding of the condition, what to expect with interventions and treatments, the range of acceptable and practical alternative care plans, and likely outcomes of each option.⁴¹ Only then can adolescents fully participate as partners in their health care.

Enhanced understanding provides a sense of control, which in turn mitigates fear, reducing the harms associated with illness and injury. Moreover, if the child is asking about the condition, he or she often already knows something is wrong and is checking to see whom to trust. Children who do not ask should be given the opportunity to receive information, but if they refuse it, information should never be forced on them. Parents are also apparently harmed in the aftermath of nondisclosure to their children. A study of bereaved parents in Sweden indicates that all those who spoke openly with their children had no regrets, whereas 27% of those who did not speak to their children about dying not only regretted their decision but also suffered from an increased incidence of depression and anxiety as a result.⁴² Thus, counselling parents about the benefits of disclosure should be raised when they are reluctant to speak with their child about illness or death.

It occasionally happens that the child's choice and parents' choices are discordant. Expecting children to adhere to adult priorities and preferences may be illogical; Ladd and Forman argue that adults' priorities clearly change over the trajectory of adulthood.⁴³ Thus, if no value set is static, a child's seemingly trivial or superficial judgments may be just as legitimate as any other. For example, the values with which adolescents judge their options are applied to an adolescent who holds those values, not to an adult with divergent values. Overriding the adolescent's decision should be undertaken with great trepidation, using the same criteria as are used to override an adult's choice.

It has been reported that children who undergo treatments for a chronic condition know the burdens of therapy more intimately than the adults trying to help them. Although they may not appreciate all the hoped-for benefits, their input into treatment decisions is clearly critical for a balanced weighing of the benefit-burden test.⁴⁴ When adolescents are able to appreciate the hoped-for benefits, they then also have the capacity to make full-fledged decisions regarding whether to forgo medical interventions. Decisions made by adolescents to refuse life-prolonging treatments have been upheld in courts of law.⁴⁵

³⁹ Canadian Paediatric Society, Bioethics Committee. (2004). Treatment decisions regarding infants, children and adolescents. *Paediatr Child Health*. 2004;9(2):99–103

⁴⁰ American Academy of Pediatrics, Committee on Bioethics. Informed consent, parental permission, and assent in pediatric practices. *Pediatrics*. 1995;95(2):314–317

⁴¹ Michaud PA, Suris JC, Viner R. The adolescent with a chronic condition. Part II: healthcare provision. *Arch Dis Child*. 2004; 89(10):943–949

⁴² Kriebel U, Vladimarsdottir U, Onelov E, Henter JI, Steineck G. (2004). Talking about death with children who have severe malignant disease. *N Engl J Med*. 2004;351(12):1175–1186

⁴³ Ladd RE, Forman EN. Adolescent decision-making: giving weight to age-specific values. *Theor Med*. 1995;16(4):333–345

⁴⁴ ⁴⁴ Feudtner, C. (2007). Collaborative communication in pediatric palliative care: a foundation for problem-solving and decision-making. *Pediatric Clinics of North America*. Vol 54. 583-607.

⁴⁵ NEED REFS HERE....

Delivering bad news

Bad news can be defined as “pertaining to situations where there is a feeling of no hope, a threat to a person’s mental or physical well-being, a risk of upsetting an established lifestyle or where a message is given that conveys to an individual fewer choices in his or her life.”⁴⁶ Greater attention to the empathic delivery of bad news will result in improved skills when the stakes escalate, as in terminal conditions.⁴⁷ Paediatric specialists have significant-to-profound discomfort in discussing prognosis, particularly the impending death of their patients by cancers.⁴⁸ Unfortunately, sometimes traumatic circumstances in ICU settings can mean that the bereaved family of trauma victims have reported being told of the death in the hallway, waiting room, or other public area, implying a lack of training of emergency and surgery personnel. When information is delivered poorly or insensitively, parents perceive a lack of empathy and respect, and memories of this experience may be etched in the minds of the survivors for the remainder of their lives, compounding and prolonging the grieving process.⁴⁹

Most of the advice about breaking bad news in general applies to the ICU, ED, and delivery room settings and to the disclosure of terminal illness. The main difference is the time frame and the intensity of emotion, although even parents of chronically ill children who have survived many previous hospitalisations will also often be shocked (and frequently unbelieving) that the child will not recover this time (“We’ve been told that before, and he is still here”). Many clinicians believe there is no good way to give bad news. However, research with parents whose children had a wide range of diagnoses provides consistent guidance.⁵⁰

When hearing bad news, parents value a doctor who clearly demonstrates a caring attitude and who allows them to talk and to express their emotions. One effective opening to the conversation is to ask, “What do you already know about what is happening to (patient’s name)?” Once they are provided with an opportunity to express what they are thinking and feeling, misperceptions should be corrected.⁵¹ Asking whether they know someone else with this diagnosis or situation and inquiring about their associated experience may also be helpful. The latter question seeks further information indirectly and the doctor may become more aware of the family’s fears and expectations. Pointing out how the child’s situation is similar to or different from the previous (or known) experience helps parents to better understand the child’s likely course.

⁴⁶ Girgis A, Samson-Fisher RW. Breaking bad news: consensus guidelines for medical practitioners. *J Clin Oncol.* 1995;13(9):2449–2456

⁴⁷ Levetown, M. (2008). Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information. *Pediatrics:* 121, 5. May 2008.

⁴⁸ Hilden JM, Emanuel EJ, Fairclough DL, et al. Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology survey. *J Clin Oncol.* 2001(1);19:205–212

⁴⁹ Field MJ, Behrman RE, eds. (2003). *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families.* Washington, DC: National Academies Press.

⁵⁰ Greenberg LW, Jewett LS, Gluck RS, et al. Giving information for a life-threatening diagnosis: parents’ and oncologists’ perceptions. *Am J Dis Child.* 1984;138(7):649–653; Girgis A, Samson-Fisher RW. Breaking bad news: consensus guidelines for medical practitioners. *J Clin Oncol.* 1995;13(9): 2449–2456; American Academy of Pediatrics, Committee on Pediatric Emergency Medicine. Death of a child in the emergency department. *Pediatrics.* 1994;93(5):861–862; Soreff SM. Sudden death in the emergency department: a comprehensive approach for families, emergency medical technicians, and emergency department staff. *Crit Care Med.* 1979;7(7):321–323; Buckman R, Kason Y. *How to Break Bad News: A Guide for Health Care Professionals.* Baltimore, MD: Johns Hopkins University Press; 1992; Woolley H, Stein A, Forrest GC, Baum JD. Imparting the diagnosis of life-threatening illness in children. *BMJ.* 1989; 298(6688):1623–1626

⁵¹ Levetown, M. (2008). Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information. *Pediatrics:* 121, 5. May 2008.

Parental dissatisfaction with the process of breaking bad news is common.⁵² Comprehensive guides for breaking bad news are available.⁵³ Although needing to inform parents of a chronic, incurable diagnosis may challenge a doctor's feelings of competency, parents are most attentive to the affective relationship of their informant, rather than the ability of the informer to "fix it." Parents' trust of advice is built by acknowledging the grief, anxiety, and fear the family is experiencing and inviting them to share their feelings and ask questions. Gradually sharing additional illness and treatment information, supplemented by written or taped materials, and providing a means to contact the physician when additional questions arise, is also greatly appreciated.⁵⁴

Parents want hopeful and positive things said about their child, and an opportunity to touch or hold the child, particularly newborn infants or children from whom they have been separated during a transport. They need recognition by the physician of the child's unique value as an individual first and as an ill or injured person second.⁵⁵ Speaking of the child as if he or she "is" the diagnosis is unhelpful and potentially damaging to a productive doctor-family relationship. As time progresses, parents also appreciate emotional support and affirmation of their efforts and ability to care for the child. "Your child is lucky to have you for parents! I can't imagine anyone doing a better job than you two!" Harsh or judgmental statements about the child, the parents, or their behaviours must be avoided.

Bad news in the ED

In emergency departments, parents often arrive separately from the child. If they are available by telephone, let them know the child is seriously ill/injured, but do not disclose death over the telephone unless the parent insists. Suggest they come in as soon as possible and bring their spouse and a close friend with them. Ask them to be careful and to consider letting someone else drive, because they are at an increased risk of having an accident because of their appropriately upset emotional state.

If a child is undergoing resuscitation when the parents arrive at the ED, assess whether it may be appropriate to offer the parents the opportunity to be with the child.⁵⁶ The majority of families offered this option accept and feel much better knowing that "everything was done" and that they were there in the child's last moments of life.⁵⁷ Parents should be made aware that they do not have to go into the resuscitation area if they choose not to. Reassurance should be provided loving and good parents decide either way. If the parents choose to be present, a staff member should be assigned as a dedicated support person. Ideally, this person should be a member of the immediate health care team and

⁵² Levetown, M. (2008). Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information. *Pediatrics*: 121, 5. May 2008.

⁵³ Boyd JR. A process for delivering bad news: supporting families when a child is diagnosed. *J Neurosci Nurs*. 2001;33(1):14–20

⁵⁴ Garwick AW, Patterson J, Bennett FC, Blum RW. Breaking the news: how families first learn about their child's chronic condition. *Arch Pediatr Adolesc Med*. 1995;149(9):991–997

⁵⁵ Krahn GL, Hallum A, Kime C. Are there good ways to give 'bad news'? *Pediatrics*. 1993;91(3):578–582

⁵⁶ Hanson C, Strawser D. Family presence during cardiopulmonary resuscitation: Foote Hospital emergency department's nine-year perspective. *J Emerg Nurs*. 1992;18(2):104–106; Doyle CJ, Post H, Burney RE, Maino J, Keefe M, Rhee KJ. Family participation during resuscitation: an option. *Ann Emerg Med*. 1987;16(6):673–675; Adams S, Whitlock M, Higgs R, Bloomfield P, Baskett PJ. Should relatives be allowed to watch resuscitation? *BMJ*. 1994;308(6945):1687–1692; Henderson DP, Knapp JF. Report of the National Consensus Conference on Family Presence During Pediatric Cardiopulmonary Resuscitation and Procedures. *Pediatr Emerg Care*. 2005;21(11):787–791; Clark AP, Aldridge MD, Guzzetta CE, et al. Family presence during cardiopulmonary resuscitation. *Crit Care Nurs Clin North Am*. 2005;17(1):23–32.

⁵⁷ Boie ET, Moore GP, Brummett C, Nelson DR. (1999). Do parents want to be present during invasive procedures performed on their children in the emergency department? A survey of 400 parents. *Ann Emerg Med*. 1999;34(1):70–74; Boudreaux ED, Francis JL, Loyacano T. Family presence during invasive procedures and resuscitations in the emergency.

should advise the parents what they will see and hear, what might be occurring and why, with the knowledge that they can leave at any time.⁵⁸

If the need arises, parents should be informed that they will be asked to leave if they interfere with the health care team's function or seem to be openly distressed by being there. When in the room, the support person explains the role of each clinician present, determining whether introductions are necessary, under the circumstances. Levetown (2008) holds that the support person should advise the parents that, despite all that is going on, this is still their child (using the child's name) and that he or she may be able to hear or sense that his or her parents are present in the room. The support person can suggest the parents touch and speak to the child, assuring him or her of the family's love.⁵⁹

Death of a child in the ED

An even more challenging task is to inform families of trauma victims that their previously healthy child is dead.⁶⁰ In these situations, the most important attributes of the communication, from the parents' perspectives, are the attitude of the doctor informing the parents, the clarity of the message, privacy of the conversation, and the ability of the doctor to answer the parents' questions clearly. The literature is replete with many parents expressing positive experiences, primarily of having caring hospital and pre-hospital staff at the time of their child's death.

Levetown (2008) provides the following guidance:⁶¹

After greeting the parents and escorting them to a private area, have someone who has directly participated in the care of their child speak with them. Sit down and bring tissues. Begin by asking what they know so far. Ask when they saw the child last and what he or she was doing at that time. Explain any factual details that are known about what happened at the scene and what has been done so far in the resuscitation. Levetown (2008) proposes that there are two choices at this point.⁶²

1. Immediate notification of the death, offering to escort the parents into the room to be with the body, and explaining what was done and that the child's injuries were too severe to survive but reassuring them that everything that could have been done to save the child's life was done.
2. A staged disclosure, initially telling them that the child is very severely injured and at risk of dying, but that everything possible to save him is still being done. Tell the parents you are going to check on the rescue team's progress, leaving a team member in the room with them; make sure the rescue area is cleaned up and that the child's body is presentable. Leave some of the tubes in place to demonstrate the efforts that were made to save the child's life. Call the chaplain and the social worker if they are not on the scene. Then, go back and inform the parents of the child's death a few minutes later.

In the case of sudden, unexpected, and overwhelming illness or death, parents will likely be shocked, highly emotional, angry, and suspicious. This reaction, although difficult to

⁵⁸ Levetown, M. (2008). Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information. *Pediatrics*: 121, 5. May 2008.

⁵⁹ Ibid. pp. e1448-e1449

⁶⁰ Levetown M. (2004). Breaking bad news in the emergency department: when seconds count. *Topics Emerg Med*. 2004;26(1):35–43

⁶¹ Ibid. p. 38.

⁶² Levetown, M. (2008). Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information. *Pediatrics*: 121, 5. May 2008.

endure as the perceived target of their animosity, is certainly understandable.⁶³ Offer to take parents in to see their child, and ensure a member of the resuscitation team is available to provide the specifics of what was done and to answer any questions. If feasible, move the body and the family to a private area to maximise privacy and minimise disruption; allow families to have some private time with the body. Ensure an appropriate environment, including a rocking chair, support persons from the family, and a limited number of members of the care team, if desired by the family. Do not rush them. Experience indicates that 2 to 3 hours is the maximum time most families want to remain with the body; 15 to 20 minutes is more common.⁶⁴

Bad news in the delivery room

Despite increasing accuracy and availability of prenatal diagnosis, a paediatrician can be confronted in the delivery room by a child who is too immature to survive or who has anomalies that are incompatible with life; attempts at resuscitation would be inappropriate in these situations.⁶⁵ When prematurity is the problem, the parent is generally already aware of this. Levetown (2008) recommends the following introductory statements to “break the ice”.⁶⁶

“I am Dr. _____ and I am the paediatrician who was called by your doctor to care for your infant. My team and I have experience doing everything possible to help premature newborns. Based on your history and our examination, it seems, unfortunately, that your daughter was born too early to survive for very long, no matter what we do. (Pause) I am sorry. I really wish it were different. At this point, we are ensuring her warmth and comfort. (Pause) Does she have a name? Would you like to spend some time with her and hold her?”

According to Levetown (2008) it is important to point out the infant’s normal features. Important things not to say at his time include asking when the mother noted her premature labour or asking about factors that may have triggered premature delivery. Blaming is unhelpful and unnecessary; avoidance of a recurrence can be accomplished at a future time when the information can be seen as helpful and can be absorbed. For the near-term child with lethal anomalies, the diagnosis has typically been made before delivery. In this case, it can be helpful for paediatricians to ask parents what they know and provide confirmation of what they see. Goals of care should have already been established. If not, or if the diagnosis is unexpected, the parents need to be informed honestly yet empathically with doctors prepared for open and clear disclosure. Hovering and whispering about the infant only adds to the panic and confusion. (Levetown, 2008)

⁶³ Todres ID, Earle M, Jellinek MS. (1994). Enhancing communication: the physician and family in the pediatric intensive care unit. *Pediatr Clin North Am.* 1994;41(6):1395–1404.

⁶⁴ Oliver RC, Sturtevant JP, Scheetz JP, Fallat ME. (2001). Beneficial effects of a hospital bereavement intervention program after traumatic childhood death. *J Trauma.* 2001;50(3):440–448

⁶⁵ Bell EF, American Academy of Pediatrics, Committee on Fetus and Newborn. Noninitiation or withdrawal of intensive care for high-risk newborns. *Pediatrics.* 2007;119(2):401–403

⁶⁶ Levetown, M. (2008). Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information. *Pediatrics:* 121, 5. May 2008.

Suggestions for “Breaking Bad News” With Skill and Empathy*

- Do not disclose bad news over the telephone.
- Use trained translators as needed.
- Avoid telling a lone parent without his or her spouse and/or a preferred support person present.
- Enable the parents to touch the deceased child before or during the interview.
- Hold or touch the child with obvious care.
- Recognise that parents are primarily responsible for their child.
- Show caring, compassion, and a sense of connection to the patient and the family.
- Pace the discussion to the parents’ emotional state; do not overwhelm them with information.
- Do not use jargon.
- Elicit parents’ ideas of the cause of the problem; ensure they do not blame themselves or others.
- Name the illness and write it down for the parents.
- Ask the parents to use their own words to explain what you have just told them to confirm effective transmission of information.
- Address the implications for the child’s future.
- Acknowledge their emotions and be prepared for tears and a need for time; it is helpful to bring a social worker and/or chaplain to the meeting.
- Be willing to show your own emotion; aloofness or detachment is offensive.
- Give parents time to be alone to absorb the information, react, and formulate additional questions.
- Be able to recommend relevant community-based resources.
- Provide contacts with other willing families with a similarly affected child.
- Provide a follow-up plan and make an appointment for the next conversation.

* Levetown, M. (2008). Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information. *Pediatrics*: 121, 5. May 2008. p. e1449.

Addressing the concerns and anxiety of parents

Because of the profound difficulties in end-of-life decision-making for dying children, the child's parents and some members of the healthcare team may find it more difficult to contemplate withdrawing life-sustaining medical treatment than to decide not to start the treatment in the first place. This may be because of the emotional distress that can accompany a decision to withdraw active medical treatment, or because they would feel responsible for the patient's death earlier. However, these anxieties should not be allowed to override clinical judgement and lead to not starting treatment that may be of some benefit to the patient, or to continue treatment that is of no overall benefit.

It should be explained carefully to the parents of the child that whatever decisions are made about providing particular treatments, their condition will be monitored and managed to ensure that they are comfortable and, as far as possible, free of pain and other distressing symptoms. There is a duty of care to ensure that the child's best interests will be upheld and protected at all times. It should also be made clear that a decision to withdraw, or not to start a treatment will be reviewed in the light of changes in the clinical situation.

Further advice about emotional and social support that may be available should be offered to the parents and other members of the family if they are finding the situation emotionally challenging. Sources of support include patient and carer support and advocacy services, translation and other cultural support services, counselling and chaplaincy services, and ethics support networks.

While acknowledging that these decisions are profoundly difficult, the paediatrician or medical officer responsible for the care of the child should ensure that the parents do not feel pressured by others in their support network to insist on or refuse particular investigations or treatments. Sufficient time should be given to allow the parents to absorb the information and that any help they need to reach their own decisions is provided in a coordinated manner.

Talking about death and dying

One of the most difficult aspects of caring for seriously ill children or adolescents is acknowledging that survival is no longer possible. The family looks to health care providers for information about the likelihood of their child's survival. When it is medically clear that a child will not survive, decisions must be made about what information to share with the parents (or person/s with parental responsibility) and how and when to share that information.

Typically, a team of professionals is involved in the child's care. Before approaching the family, members of the team first discuss the child's situation and reach a consensus about the certainty of the child's death. The team members then agree upon the words that will be used to explain this situation to the parents and the child, so that the same message can be used by all members of the team in their interactions with the family. Careful documentation in the child's medical record of team members' discussions with the patient and family, including the specific terms used, is important to ensure that all team members are equally well informed so that their care interactions with the child and family are consistent.

The greatest impediment to decision making at the end of life is the lingering uncertainty about the inevitability of a child's death. Such uncertainty, if it continues, does not allow time for a coordinated, thoughtful approach to helping the parents and, when possible, the child to prepare for the child's dying and death. Depending on the circumstances,

such preparation may have to be done quickly or may be done gradually. The child's medical status, the parent's level of awareness, and the clinician's certainty of the child's prognosis are all factors in how much time will be available to prepare for the child's dying.

The factors that help parents to "sense" that their child is going to die include visible symptoms, such as physical changes and information obtained from trusted health care professionals. Parents are assisted in making end-of-life decisions for their child when they believe that they and the health care team have done all that is possible to save the child and that everything has been done well. Throughout the transition from curative care to end-of-life care, the partnership among patients, family members, and health care professionals must be continually facilitated to ensure that end-of-life care is optimal.

Although there is little research-based information about end-of-life decision making and family preparation, evidence-based guidelines for decision making are available. While some studies and clinical reports support the inclusion of adolescents in end-of-life discussions and decisions, there are no studies that examine the role of the younger child. Clinical reports do, however, support the idea that younger children are very much aware of their impending deaths, whether or not they are directly included in conversations about their prognosis and care.

Health care professionals uphold that continuous communication be maintained between the parents and the health care team about the status of the dying child. Parents may react to their child's terminal status in various ways, including denial. If parents appear to be in denial, it is important to ensure that they have been clearly told of their child's prognosis. Parents and other family members often vacillate between different emotional responses and seek opportunities to discuss and re-discuss their child's situation with the health care team.

Parents will often want to know when their child will die and exactly what will occur. Although it is difficult to predict when a child will die, useful information can be given about symptoms the child is likely to experience, such as breathing changes, decreasing appetite, and decreasing energy. Most importantly, parents will need to be assured that their child will be kept comfortable and that members of the health care team will be readily available to the child and the family.

Siblings may exhibit a variety of responses to the impending death of a brother or sister. These responses will be influenced by the sibling's age and developmental maturity, the length of time the dying child has been ill, and the extent to which the sibling has been involved in the patient's care. Siblings need to be told that it is not their fault that the brother or sister is dying. Siblings have indicated their need to be with the dying sibling and, if possible, to be involved in the sibling's daily care; if these are not possible, they need at least to be informed regularly about the status of their dying sibling.

Usual Method of Communicating Message	How the Usual Communication may be Perceived	Alternative Method of Communicating Message
Do you want us to do CPR?	CPR would work if you would allow us to do it	<ul style="list-style-type: none"> • Tell me what you know about CPR. • CPR is most helpful for patients who are relatively healthy, and even then, only 1 of 3 patients survive. If your child's heart were to stop, it would not be because there is a problem with their heart, it would be because they are dying. • Pumping on your child's heart, or doing CPR, will not make them better. • While I would recommend not doing CPR, I am not recommending stopping any other treatment your child is currently receiving. • Let's hope for the best, but plan for the worst. We will need to keep a close watch on your child and keep you up to date on how they are doing. • Do you have any questions? • Let's talk again later today so I can update you.
Let's stop heroic treatment	We will provide less than optimal care	<ul style="list-style-type: none"> • At this time, I think the most heroic thing we can do is to understand how sick your child is and stop treatments that aren't working for them. • I think we should do all we can to ensure your child's and your own comfort, make sure there are no missed opportunities, and ensure we properly celebrate your child's life. • Some ideas that have helped other families include getting your child home with help for you if you wish, or have your friends and family come to the hospital to visit.
Let's stop aggressive treatment	We will not be attentive to your child's needs, including symptom distress and need for comfort	<ul style="list-style-type: none"> • We will do all we can to ensure your child is as comfortable as possible.
Your child has failed the treatment	The patient is the cause of the problem	<ul style="list-style-type: none"> • We have tried all the proven treatments and even some experimental ones for your child. Unfortunately, we did not get the results we had hoped for.
We are recommending withdrawal of care for your child	We are going to abandon your child and you	<ul style="list-style-type: none"> • Your child is too ill to get better. We need to refocus our efforts on making the most of the time your child has left.
There is nothing more we can do for your child	We will allow your child to suffer, we do not care about your child, we only care about fighting the disease	<ul style="list-style-type: none"> • We need to change the goals of our care for your child. At this point we clearly cannot cure your child, but that does not mean we can't help your child and your family.
Your child is not strong	Your child is weak	<ul style="list-style-type: none"> • Your child is strong and has fought hard with us

⁶⁷ Levetown M. (2008). Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information. *Pediatrics*. Volume 121, Number 5, May 2008, p. e1452.

Usual Method of Communicating Message	How the Usual Communication may be Perceived	Alternative Method of Communicating Message
enough to keep going		<p>to beat this disease.</p> <ul style="list-style-type: none"> • As much as we wish we could, we cannot cure your child. • At this point, we are hurting your child rather than helping, giving them side effects, and keeping them from being at home with family, or doing what they really want to do with the time they have left.
We will make it so that your child does not suffer	We are going to kill your child	<ul style="list-style-type: none"> • We will do everything we can to make your child comfortable.
We need to stop active treatment for your child	We will not take care of your child at all	<ul style="list-style-type: none"> • The goal of curing your child's disease, despite the best efforts of a lot of hard-working people, is no longer possible. • I have cared for many children as sick as your child. It is very hard on all of us, especially you, when the treatments do not work as we hoped. • Many parents like you have agreed to stop efforts to cure when they are not working, as difficult as that is. • <i>Optional: would you like me to put you in touch with some of the other parents who have been through this too?</i>
Do you want us to stop your child's treatment?	You are the final arbiter of your child's death	<ul style="list-style-type: none"> • Your child is lucky to have such excellent, loving and selfless parents. • I know this is hard; we will get through it together. • I am glad you agree with our recommendations to change the goals of care to better meet your child's needs. • I will let my team know what we have decided.
I am glad you agree. Will you sign this to say your child will not be provided with CPR?	You are signing a death warrant	<ul style="list-style-type: none"> • There is no surgery, no medicine, and all the love you clearly feel for your child will not make them better; your child is just too sick. • I will change your child's orders to make sure they only get tests and treatment that can help them now.

Talking to parents

The following open-ended questions are a good starting place to begin to understand the parent's perspectives.

- Tell us about your child before he/she became ill.
- What makes your child happy? Sad?
- What is your understanding of your child's illness/condition?
- What have the past few weeks or months been like? What are you anticipating?
- What are your hopes? What are your worries?
- In light of your understanding of your child's illness, what is most important to you and your family?

Talking to children

When a child is facing a life-threatening condition, parents are the legal decision makers about treatment options, including the introduction of palliative or hospice care services. However, children should be involved in their treatment decisions at a developmentally appropriate level. Even young children can voice their preferences about treatment and care decisions. Helping children understand what is happening to them physically, emotionally, and spiritually facilitates their comfort and reduces their anxiety. In particular, adolescents with terminal illnesses want to be involved in the medical decision-making process.

Children report that they are more comfortable with physicians who take the time to communicate with them directly. The following are age-appropriate tips when talking with children.

Children 2 to 5 years of age:

- Simple, concrete information with adequate age-appropriate explanations
- Comfort, reassurance, and the constant presence of caring family members
- Involving parents in care and explanations
- Answering questions calmly and with examples
- Using play, puppets and dolls, expressive therapies, and storytelling for teaching and expression of emotion
- "Checking in" about the child's understanding

Children 6 to 9 years of age:

- May become preoccupied with details and ask the same questions repeatedly
- May feel responsible for the illness and need to be reassured that this is not their fault
- Continue to find family to be very important and are reassured by the constant presence of caring family members
- Still think concretely but benefit from more information about what is happening to them
- Benefit from reading, playing, drawing, art, and music as appropriate modalities of intervention

Children 10 to 12 years of age:

- Become very aware of feeling different around their peers at school
- May exhibit stoic and brave responses in an attempt to protect their parents and caregivers
- Benefit from a safe environment to explore fears, hopes, and expectations
- May benefit from meeting with other children or caregivers away from their parents
- May try to protect their parents and family

- May benefit from reading, playing, drawing, art, and music interventions, along with peer-based support

Talking to adolescents

- Display a wide range of response to facing critical and life-threatening illness
- Feel caught between finding independence and feeling the pull of dependence that can be brought on by illness
- May have difficulty talking with non-ill peers because they feel "different"
- Benefit from being matched with other adolescents also facing illness
- Benefit from activity-based groups not focused on illness
- Benefit from useful creative outlets, including art, dance, music, videography, blogging, and writing

Advance care planning for children

As treatment and care towards the end of life are delivered by multidisciplinary teams often working across local health, social care and voluntary sector services, you must plan ahead as much as possible to ensure timely access to safe, effective care and continuity in its delivery to meet the patient's needs. The emotional distress and other pressures inherent in situations in which patients are approaching the end of their life sometimes lead to misunderstandings and conflict between doctors and patients and those close to them, or between members of the healthcare team. However, this can usually be avoided through early, sensitive discussion and planning about how best to manage the patient's care.

What to discuss

Patients whose death from their current condition is a foreseeable possibility are likely to want the opportunity (whether they are in a community or hospital setting) to decide what arrangements should be made to manage the final stages of their illness. This could include having access to palliative care, and attending to any personal and other matters that they consider important towards the end of their life.

If a patient in your care has a condition that will impair their capacity as it progresses, or is otherwise facing a situation in which loss or impairment of capacity is a foreseeable possibility, you should encourage them to think about what they might want for themselves should this happen, and to discuss their wishes and concerns with you and the healthcare team. Your discussions should cover:

1. the patient's wishes, preferences or fears in relation to their future treatment and care
2. the feelings, beliefs or values that may be influencing the patient's preferences and decisions
3. the family members, others close to the patient or any legal proxies that the patient would like to be involved in decisions about their care

4. interventions which may be considered or undertaken in an emergency, such as cardiopulmonary resuscitation (CPR), when it may be helpful to make decisions in advance
5. the patient's preferred place of care (and how this may affect the treatment options available)
6. the patient's needs for religious, spiritual or other personal support.

Depending on the patient's circumstances, it may also be appropriate to create opportunities for them to talk about what they want to happen after they die. Some patients will want to discuss their wishes in relation to the handling of their body, and their beliefs or values about organ or tissue donation.

You must approach all such discussions sensitively. If you are unsure how best to do this or how to respond to any non-clinical issues raised by the patient, you should refer to relevant guidelines on good practice in advance care planning. If the patient agrees, you should involve in the discussions other members of the healthcare team, people who are close to the patient, or an independent advocate.

Recording the child's wishes in an advance care plan

If a patient wants to nominate someone to make decisions on their behalf if they lose capacity, or if they want to make an advance refusal of a particular treatment, you should explain that there may be ways to formalise these wishes, such as appointing an attorney or making a written advance decision or directive. You should support a patient who has decided to take these steps. You should provide advice on the clinical issues and recommend that they get independent advice on how to formalise their wishes.

You must make a record of the discussion and of the decisions made. You should make sure that a record of the advance care plan is made available to the patient, and is shared with others involved in their care (provided that the patient agrees), so that everyone is clear about what has been agreed. If a patient makes an advance refusal of treatment, you should encourage them to share this information with those close to them, with other doctors, and with key health and social care staff involved in their care.

Medical decision-making and goals of care

During the course of a life-threatening condition, there are opportunities to intervene with medical therapies of uncertain benefit. The decision to implement such interventions needs to be considered within the context of the goals of the child and family.⁶⁸ The following steps are useful in achieving a good decision.

- Identify the likelihood of an intervention meeting the goals of care of the patient and family.
- Know and discuss the evidence for the possible benefit and harm for the interventions available.
- Define a time period in which the intervention would be expected to meet the identified goals.

⁶⁸ American Academy of Pediatrics. Committee on Bioethics and Committee on Hospital Care. Palliative care for children. *Pediatrics* 2000; 106:351

- Discuss a back-up plan in case the hoped for benefit does not occur or increased suffering occurs. This may include stopping the treatment or shifting the overall focus from curative treatment to comfort measures.

To avoid misunderstanding, during these discussions, it should be made clear to the family that the care team is not trying to limit treatments that have reasonable benefit. The goal is to protect the child from interventions with little or no benefit that may harm or prolong suffering, and to provide care that maximizes comfort throughout the child's life.

The health care team and family need to establish patient-centered goals of care with attention to relief of the child and family's distress. The goals of caring for a child with a terminal condition do not necessarily exclude the goals of disease-directed therapy. For example, children with cancer and their parents often have simultaneous goals for palliative care to lessen suffering and for cancer-directed therapy to extend life.

The child's best interests should be the primary guide. The role of the parents and the health care team is to watch, listen, and reflect honestly on what is in the best interest of the child and what will promote their well-being. This process includes a reflection on the benefits and adverse effects of past interventions, and the expected outcome of current and future treatment. The following series of questions/issues are useful to consider and review with families while developing goals of care that can help instruct care plans.

Goals of care

Recommended questions

- Goals often identified by children and their families include comfort and quality of life. Are there other goals that are important to you (your child) and your family?
- We know that children and their parents often have concerns that may change over time. These may include: Will I (my child) get better? Is there more that could be done? What are some of your worries?
- Are you seeing less benefit with less return to prior baseline over time, from available chronic and acute treatments (eg, longer periods of illness or a shorter time between each episode)?
- How much are you (is your child) able to enjoy the things that are important to you (your child), such as relationships and activities?
- What percent of each day or week are you (is your child) experiencing suffering?
- If it would be helpful today, we can talk through some of the "what ifs" so as to address any worries you may have and to allow you to focus on loving your child. This may include discussing what to expect and developing a care plan for potential future needs, such as maintaining comfort.
- We will carefully review whether interventions being considered will maintain or improve health, meet goals of care, or prolong a process of decline or suffering.

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