

Decision-Making at the End of Life in Infants, Children and Adolescents

A Policy of the Paediatrics & Child
Health Division of The Royal
Australasian College of Physicians



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Executive Summary

Decision-making at the end of life in children does not lend itself to a prescriptive approach, but rather it requires an individualised style determined by the facts of each case. This policy recognises that a range of experience exists amongst Fellows and that the majority of interactions already come to an acceptable conclusion. However, it also acknowledges that decision-making at the end of life is stressful for all participants and that unique complexity can exist to make the process difficult, with the risk of an unsatisfactory outcome. In either situation this document should be embraced as a collegial support and resource to guide individual practice and inform any locally developed policy and guidelines.

The cornerstones of good decision-making include collaboration, effective communication and cognisance of the ethical principles relating to children, along with an understanding of the developmental stage of the child. A collaborative, multi-disciplinary approach often offers valuable insights into the child and their family/whanau. These perspectives can enlighten the style and pacing of communication with the child and family/whanau strengthening the potential for a reasonable conclusion and prevention of conflict.

End of life decisions should be made with consideration of the concepts of non-maleficence, advocacy of best interest, and appreciation of the philosophical approach of palliative care along with the evolving nature of autonomy and competence in children. The discussions are best held at the earliest opportunity as there is good evidence to suggest that this improves quality of life through timely access to palliative care, often allowing the child and their family/whanau to express their wishes and achieve personal goals. This is best achieved through open, honest communication from a lead person who is senior, accessible and who has a clear understanding of the medical and family/whanau issues and is able to answer any clinical questions that arise. The channels of communication should be formally addressed and be made clear to all.

The discussions with the child and their family/whanau are ideally undertaken over time with repeated conversations. However, time pressures can exist in acute or unexpected circumstances such as is not uncommon in the neonatal unit, emergency department or intensive care environment. These scenarios can be further complicated by the dilemma of prognostic uncertainty. That does not mean decisions around children with more protracted illnesses can not be problematic, as highlighted by children with severe neurological impairment, where the intangible and subjective concept of quality of life can introduce disparate points of view.

This policy was developed by drawing on the scientific and legal literature, international guidelines and policy documents, and from health professional and consumer experience through wide consultation. Consultation stressed the need for the policy to be widely disseminated. Fellows of all levels of experience are encouraged to add a regular communication skills training package to their professional development programme.

Recommendations

Training

The RACP believes that communication skills training is an essential element of learning at every phase of medical training.

Accordingly the RACP will work with professional bodies to:

1. Promote communication skills training at all levels of medical training.
2. Create and facilitate the development of training opportunities for trainees in communication and decision-making.
3. Promote continuing professional development for Fellows in communication skills, and provide regular opportunities for professionals to update their skills.

Professional Practice

The RACP believes that this is an important area for all Fellows to maintain and enhance their skills.

Accordingly the RACP supports:

1. Fellows regularly updating their communication skills through certified courses as a core component of ongoing professional development.
2. Fellows having a format to assess competency in children and to be aware when formal assessment is required.

Introduction

Working with children and their family/whanau faced with life limiting or life threatening illness is one of the most challenging, yet potentially most rewarding, aspects of paediatric practice. These guidelines are written to aid clinicians involved in the care of infants, children and adolescents at the end of life. They are intended as a resource and guide to accepted practice in Australia and New Zealand and should be informed by locally developed policies and guidelines that take into account local circumstances, culture and practices.

Overall, decisions are primarily driven by the facts of each case and the circumstances and beliefs of each family/whanau. Treating teams, and the family/whanau, involved must be free to explore all available options in order to find the best solution for the child concerned. The decisions which teams and family/whanau are sometimes required to make may transcend the boundary of our medical and moral knowledge and take us into areas of uncertainty where interpersonal respect and empathy has to be exercised.

Inherent in this is the necessity to accept that complete certainty can not be achieved for some decisions. The quest for such certainty may lead to a paralysis of decision-making and, as a result, adverse consequences for the child and family/whanau.

For the purposes of this document, the term child or children covers the age range 0-18 years and the term family/whanau includes the child.

Principles

Respect for life

The goal to preserve life must be tempered by the duty of not doing harm (non-maleficence) that is not preserving life at all costs. If death is inevitable or if ongoing treatment will cause more harm than benefit then the focus of care should shift along the continuum to the palliation of symptoms and relief of suffering.¹

Best Interest

Clinicians and guardians, usually parents, have a duty to make all key decisions in the best interest of the child. The treating team must always see itself as an advocate for the interests of the child and be prepared to manage differences with the parents from this perspective.

Palliative care

Palliative care for children is a process applicable to children with life limiting or life threatening conditions that may lead to their early death over a relatively short (days, weeks or months) or long (years) time frame. The principles have been defined by the World Health Organization as ²: *The active and total care of the child's body, mind and spirit, and also involves giving support to the child's family.*

- It begins when illness is diagnosed, and continues regardless of whether or not a child receives curative treatment directed at the disease.

- Health providers must evaluate and alleviate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family/whanau and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

In addition, care should embrace the cultural element of the family/whanau.

Autonomy and Competence

It is a well accepted tenet that the competent adult will choose how their condition is to be managed and, under normal circumstances, no treatment can be undertaken without consent. For a child to be considered autonomous, they must want to participate in the decision-making process and have the developmental capacity to think, decide and act on the basis of such thought, free from pressure or coercion.³

A child's competence to participate and make an informed choice is based on their having an understanding of their illness as well as the risks and benefits of treatment and non-treatment.^{4 5} Competence, like all forms of cognition, develops over time depending on the individual and it is important not to prejudge a child based on their age, as children living with a life threatening illness often possess a maturity beyond their chronological age. The older child, depending on maturity and family/whanau support, will often be able to influence or determine their treatment and should be actively encouraged to participate in decision-making.

The child's ability to competently participate can be categorised into one of four areas:

- being informed
- being consulted
- having views taken into account in decision-making
- being respected as the main decision-maker.^{6 7}

Many children do not have the capacity to consent, either because they are too young or too sick to participate in the decision-making process. Parents are generally the best advocates for their child and are most likely to decide in the child's best interests. They may, however, have conflicting priorities and demands that influence their ability to make a decision in the best interest of their child. The reasons may not be apparent at the time and makes the involvement of psychosocial support important. If there were a concern that a competent child was not able to express their view, for whatever reason, then this should be addressed through psychological evaluation or the use of an independent advocate for the child.

Right to Information and Choice

The family/whanau has the right to honest and accurate information about the condition, prognosis and management options in a timely fashion. They also have the right to receive this information in a sensitive way, allowing them time and opportunity to understand and participate as fully as they can. In this environment the child and family/whanau are helped to express their feelings, providing valuable insight into their illness beliefs, expectations and wishes. This may in turn allow, more specifically, children to express their choices in regards to management options.

Equitable Care

Care should be available to all, regardless of ethnicity, religion, or social status. There is an obligation to explore, respect and adapt care/decision-making to the culture and beliefs of the family/whanau, as long as this remains within the law and the child's best interests.

This may entail considerable research and professional development to allow team members to develop sufficient understanding of the widely diverse cultural and religious belief systems around death. Religions and cultures are not uniform and it is important to avoid stereotypical views, as the meaning and application of beliefs may vary widely within a given group. Much of this can be clarified by listening to the family/whanau and by engaging counselling or appropriate religious or cultural support.⁸

Similarly, health professionals bring their own ethical, religious and cultural beliefs to the care of children. Differences in opinion and interpretation surrounding management may be framed by these values. An openness to discuss these differences, perhaps with formal facilitation, may allow issues to be resolved and help shift the focus back to the needs of the family/whanau.

Decision-making may also involve the need for exploration of different family/whanau structures and models of decision-making. The model of the western "nuclear family" in which power resides with the parents, may not be universally applicable. The main decision-making capacity may be overseen by the extended family/whanau with the parents not playing a defining role. If decision-making is to be appropriate and effective, it may be necessary to engage more widely with the extended family/whanau and their community.

Local policies should be in place to acknowledge the specific requirements of indigenous peoples, Maori, Aboriginal and Torres Strait Island peoples^{9 10} and new migrant populations.

Support and Professional Development

Professional development is a universal obligation for all health professionals. It is particularly important in the area of decision-making at the end of life because of the potential complexity of issues and the need for effective communication.

A variety of supports should be available for those involved in decision-making. This could take the form of immediate peers, colleagues from other disciplines, for instance social work, psychology, pastoral care and ethics or could involve more formal self care measures such as supervision.

Rights and Duties of Health Care Professionals

The role of the health professional is to care for the family/whanau, while facilitating the process of decision-making around the child's care and maintaining a relationship of trust and respect. The role also entails a responsibility to colleagues, to support and respect them in dealing with difficult situations, even during disagreement.

Health professionals have a duty to argue their views concerning management choices but there is also an obligation to respect group decisions and the decisions of the family/whanau, regardless of personal beliefs. Personnel disagreeing with decisions

should, however, have the opportunity to be heard, supported and to choose not to be involved in effecting such decisions so long as this choice does not adversely affect the care of the child and family/whanau.

Withholding and Withdrawal of Treatment

Withholding or withdrawing therapy is considered together as there are no legal or morally relevant differences between the two actions.¹¹ In practice, however, it would be fair to say it is often more difficult to withdraw a therapy than to withhold one. These should be considered when use of life-sustaining treatment is no longer appropriate.

This may occur when:

- death is imminent
- treatment would be ineffective making life intolerable because of pain and suffering
- life would be shortened regardless of treatment and non-treatment would allow for increased comfort.

The key consideration around making a decision to withhold or withdraw a treatment is a decision not to provide a treatment which no longer confers benefit to the patient. Most cultures accept that it is not appropriate to pursue treatment at all costs.

All forms of medical intervention can be withdrawn or withheld including resuscitation measures, provision of artificial hydration and nutrition and administration of antibiotics. It is, however, important to remember that the decision to withhold or withdraw a particular intervention does not imply that all care should cease.¹² It is also important that decisions be within the bounds of good medical practice and likely to be supported by a responsible body of medical opinion.

Resuscitation Orders

Resuscitation orders and policies around resuscitation status have long been associated with Do Not Resuscitate (DNR) orders. They provide for an opportunity to have a frank discussion and allow for clear end of life decision-making. However, they can often be perceived negatively by the family/whanau as they, more often than not, focus on what should not be done. To avoid this Do Not Attempt Resuscitation (DNAR) or Allow Natural Death (AND) orders that include measures that **SHOULD BE** performed for the child have been introduced. The AND discussion addresses the intensity of management from the perspective of the child's quality of life and what is in the child's best interest, concepts with which parents can often work more easily.

Resuscitation status should be addressed early as the family/whanau may require multiple discussions to gain agreement on the goals of care before an order can be instituted. Failure to discuss the issue can lead to aggressive resuscitation being performed unnecessarily or may result in inadequate time to come to terms with the decision, leading to feelings of guilt and regret for the family/whanau.^{13 14} Disagreement over a child's resuscitation status is addressed later (**see Conflict and Resolution**).

The resuscitation order can be used to limit levels of resuscitation thought to be harmful or unproductive in a specific clinical circumstance. They may take the form of a decision to avoid re-ventilation, or to ventilate only in defined circumstances such as during a respiratory deterioration due to an acute, reversible illness in a child with Duchenne muscular dystrophy.

The decisions must be tailored to the clinical circumstance of the individual child and be seen as dynamic, changing with the alteration of management goals in the course of ongoing discussion. All such decisions should be clearly documented in the medical notes and, ideally, in care plans and handover sheets. All changes in the care plan should be sequentially documented, with clear definition of key decision-makers and contact persons.

It is important to remember that obtaining resuscitation orders is only a small part of the discussions involved in end of life care.

Artificial Hydration and Nutrition

Offering nutrition and hydration by mouth is a basic care and is fundamental to keeping an individual comfortable. The considerable debate that exists tends to focus on the use and extent of artificial hydration and nutrition at the end of life. Clarity can be brought to this debate if the focus shifts from assessing the justification for withdrawing or withholding treatment to considering whether the benefits of treatment for the child justify the intervention.

The method used to feed has moral and legal relevance. If 'feeds are given with invasive intervention (nasogastric tube feeding, gastrostomy feeding, total parenteral nutrition) to bypass pathology in the swallowing process', it constitutes medical treatment and can be viewed as an extraordinary measure.⁶ It is open to scrutiny and can be refused by a competent adult or proxy. This has been established in recent Australian legal judgments and may be applicable to children.¹⁵

Like decisions for resuscitation, decisions regarding the provision of artificial hydration and nutrition need to be individualised and reviewed in the context of the changing course of the illness based on specific goals of management, particularly during the terminal phase.

Symptom Management in Advanced Illness

The goal of care at the end of life is to ensure comfort and relief from pain and suffering whilst maintaining maximum function. There are occasions when medications to relieve suffering, such as sedatives and/or analgesics, need to be titrated to such levels that cognitive, respiratory or cardiac functions are compromised. This may be perceived, by both the family/whanau and staff, as the medications shortening life. It may significantly complicate the decision-making process and, just as importantly, lead to the use of inadequate sedation and/or analgesia resulting in suffering.

There is evidence that analgesic or sedative medication in normally effective doses will not significantly shorten life.¹⁶ Even if shortening of life were to occur during the terminal phase, most professionals agree that sedation and analgesia used to relieve pain and suffering is entirely appropriate.

Practical Decision-Making

Collaborative Decision-Making

Collaborative decision-making is the safest and most robust model, incorporating and balancing the observations, knowledge and insights of both the family/whanau and the members of the treating team. This model allows a variety of responses and can adapt to most circumstances. It also provides an inherent system of “checks and balances” against extremes in decision-making, while providing support and validation for the conclusions of the key decision-makers.

Care of children, at any time but particularly at the end of life, is about developing a trusting, respectful partnership between the family/whanau and treating team. The team is commonly multidisciplinary in nature and may consist of doctors, nurses and allied health workers such as social workers, psychologists and therapists as well as religious, philosophical or bioethical professionals. They, along with immediate and extended family/whanau bring different sets of skills and perspectives which can enrich the process and allow for an adaptable response to most situations.

Currently, leadership tends to rest primarily with senior medical staff for fundamental decisions, definition of prognosis and alternative choices in management. This should be formally addressed in all situations so that channels of communication are clear to all, especially the family/whanau. However, being part of a collaborative multidisciplinary team functions to reduce isolation of individual members to the extent that some of this duty can be shared by the treating team. It also provides valuable support and opportunities for professional development.¹⁷ Thus involvement and perspectives from nurses, social workers, psychologists and other allied health workers and the insights of others such as pastoral care and ethics personnel may offer information less easily available to the medical team. This is supported by evidence that nurses may be the most important and influential source of information for parents.¹⁸

All staff, even if junior, should have the opportunity to provide input into decisions, as they offer the perspective of close day to day contact. There is evidence that exclusion from participation in the process may increase their stress, hamper their ability to support the family/whanau and potentially compromise their advocacy role through the changing care required.

Incorporation and Balance

The family/whanau is an intrinsic part of the collaboration and they play a key role in the decision-making process. However, for some there may be a history of challenging relationships with authority figures and institutions and the family/whanau may have become negatively stereotyped as a result.

Management should aim to separate these issues and find a way to engage productively and openly with the family/whanau. In such situations it is particularly important to simplify and clarify channels of communication and authority, and to seek to empower the family/whanau to articulate their wishes and priorities for their child.

Family/whanau dynamics may be challenging, or may be so profoundly affected by the situation in which they find themselves that they are unable to contribute to urgent decision-making. In the unusual situation where a parent is unable to make decisions,

others such as family/whanau members, legal guardians or public trustees may be nominated to the decision-making role.

Timing of Discussions

End of life decisions should be discussed at the earliest opportunity including at the time of diagnosis, to best prepare the family/whanau for the time ahead. This allows for an open exploration of the possibility of death and an opportunity for fears to be put into context. This in turn permits parents to explore choices more comprehensively than if they are introduced to this possibility once death is imminent.

There is good evidence that early discussion improves the quality of life through earlier access to palliative care and allows the family/whanau to express their wishes and achieve their personal goals.^{19 20} This dialogue can also prevent inappropriate life-sustaining medical procedures being performed.^{21 22}

Impediments to early discussion include difficulty in providing an accurate prognosis because of the unpredictable nature of the disease and clinician reluctance to consider a palliative approach, for fear it signals a loss of hope. There is, however, no evidence that early discussion causes loss of hope.²³

Development of Consensus

Whenever choices about end of life care arise it is vital to ensure a full exploration of the clinical situation and the available treatment options. This primarily involves the family/whanau and immediate treating team, with the information being formally discussed by the most senior clinician with an established relationship. However, it is important to recognise that the treating team should include relevant general or sub-specialist paediatricians particularly if they have been involved in the care of the child over a long period of time. The knowledge held from this long association can enlighten the decision-making process.

The point at which end of life care becomes a consideration is a difficult time for all, particularly the family/whanau. It is important to recognise the considerable burden faced by parents and to provide them with appropriate support to facilitate their decision-making. Adequate time and, if clinical circumstances allow, repeated discussion is important. This provides the family/whanau the opportunity to work through the initial shock, evolve a response and to organise around the new task. However, it may be unrealistic to expect all key decisions to be made at one meeting and for reliably good decision-making from the family/whanau in the initial phase.

Similarly, the treating team benefits from the opportunity for repeated exploration of decisions, which commonly allows consensus to develop. It also provides space for exploration and management of any differences or difficulties that may arise, allows for appropriate support of team members and provides time for further information to affect the decision.

The evolution of decisions often proceeds in a stepwise fashion, as information comes to light and as the family/whanau understanding and goals change. In palliative care, this often takes the form of progressive removal of intervention. For example, an initial decision not to escalate treatment further in the event of deterioration may be followed by decisions which progressively reduce the invasiveness of treatment, ultimately leading to withdrawal of intensive care with the associated opportunity for greater family/whanau interaction with the child.

The urgency of care in critically sick children as seen in the emergency room or intensive care environment may dictate a more rapid decision-making process. Nevertheless, an anticipatory discussion on the prospect of a sudden deterioration provides an avenue for the family to express their values and wishes and could facilitate the subsequent participation of the family during such an event.

Process of Decision-Making

The aim is to ensure the child gets the most appropriate care and to give the family/whanau the best opportunity to prepare for the probable poor outcome or death of their child.

Clinical Assessment

Clinical assessment must be comprehensive. This may require second opinions from other specialists or repeated sub-specialist assessment to arrive at a decision on prognosis and subsequent management. All time afforded, provides the family/whanau an opportunity to process the information they receive.

Disclosure

Disclosure of bad news is one of the more difficult aspects of clinical practice and can confront the treating team with strong feelings of failure and vulnerability.²⁴ A general guide to disclosing difficult information is described in **Appendix 1**

Disclosure can be aided by providing the family/whanau with information that explicitly outlines the risk of death, or severe disability, early on in management. This can then be incorporated into ongoing discussions. However, such a process cannot encompass all possibilities, particularly occurrences unexpected to the treating team. This situation can be hard to manage satisfactorily.

Discussion and Negotiation

Following disclosure and assimilation of the issues, a process of discussion and negotiation will usually ensue. This stage may see a shift in the goals of treatment from aggressive intervention to palliative care and result in the introduction of the palliative care team to the family/whanau. An intermediate measure, with or without palliative care involvement, is negotiation around the reduction of intervention. This provides the family/whanau time to explore their goals and allows for the opportunity for them to feel something positive has been achieved.

Negotiation may take considerable time. This may reflect a real and legitimate uncertainty about prognosis, denial and an inability to face the finality of the situation or reveal difficulties within the family/whanau in reaching a conclusion. Discussion needs to continue if these issues are to be resolved. A definitive or interim plan can be put in place as agreement is reached.

Documentation

Documenting decisions in the medical notes including the reasons for those decisions and measures to be performed (**see Resuscitation Orders**) is critical. They should also be documented in nursing and medical care plans and outlined at daily handover. This has obvious medico-legal significance, but of greater importance is its value in ensuring

consistency of management and reducing the risk of mistakes and variation from the agreed plan.²⁵

Conflict and Resolution

Disagreement is always possible when dealing with complicated and uncertain issues. The medical prognosis may not be definite and the ethics and practicalities of end of life care may be open to dispute. Some divergence of opinion is probably a realistic expectation, as difficult choices are being worked through, often in the face of inadequate information. It is unrealistic to expect complete consensus and therefore the aim is to seek as much common ground as possible, while acknowledging sincerely held differences in opinion.

Open communication between the family/whanau and the treating team will help to minimise the risk of unproductive disagreement and to allow issues to be defined and worked through. This will, hopefully, help to cement a trusting relationship between the parents and members of the treating team, even in the event of disagreement. Suffice to say any covert planning, consultation or action risks breaching the trust that has been developed.

Within the Treating Team

Disagreements within the health care team commonly centre on the medical prognosis and management options. Most of these disputes may be resolved with further information, investigation and discussion around the issues, or a second opinion from a senior clinician outside the treating team. Disagreement may also be founded on inadequate inclusion and consultation of the wider team. Inclusive discussion throughout the management of complex cases is the foundation of good practice, and is usually the best path to take in resolving concerns within the team about practical and ethical issues.

Within the Family/Whanau

Disagreement within the family/whanau is not uncommon and includes disagreement between the child and parent's as well as amongst adult family/whanau members. Repeated discussion over time to determine the beliefs, fears and conflicting goals driving the incongruity may allow resolution of the conflict or a negotiated compromise.

While it is vital to recognise and protect the central role of the parents in decision-making, some family/whanau models may require a different approach. In some cultures the extended family/whanau, may be central in either determining decisions or providing a supportive context in which the parents can explore and express their wishes. Sensitive engagement with this aspect of the extended family/whanau may facilitate progress.

The goal is to move forward at a pace which allows all key family/whanau members to take the time they need to reach agreement with, or at least acceptance of, any decisions made. This may sometimes mean delaying decisions for a few days if the condition of the child allows, enabling fuller exploration. This extra time to allow resolution and acceptance can be a valuable investment for the family/whanau.

Between the Family/Whanau and Treating Team

Family/whanau disagreement with the treating team is most commonly due to differences in perception of prognosis or difficulties in accepting bad news. There may

also be fundamental differences in beliefs or philosophy around end of life and/or quality of life. The risk of these conflicts occurring can be reduced by early open and honest communication and the provision of support from senior staff on a regular basis. This serves to minimise confusion and maximise trust, while also giving family/whanau the earliest possible warning of any deterioration in condition.

Disagreement with the team can take a number of forms, the most common being an inability to accept the withdrawal of intensive treatment. Less common is the request for cessation of treatment when the treatment is felt by the treating team to be appropriate. Whenever disagreement occurs, a senior member of the team should attempt to ascertain the cause of the disagreement as quickly as possible. Ongoing discussion and the provision of further information may allow some resolution or compromise.

Should the disagreement persist, despite multiple attempts at resolution, the choices are limited. One option when a family/whanau is struggling to withdraw treatment is to instigate a time-outcome limited trial, whereby a treatment is provided for a predetermined period. At the end of this time, the treatment is discontinued if the benefit is less than the distress caused.

Sometimes it is necessary to seek a second opinion and/or third party mediation via an ethicist or clinical ethics committee, theologian, religious advisor or pastoral care worker. The passage of time and provision of counselling, together with the evolution of clinical events (for better or worse) often enables agreement regarding a management plan.

If agreement is still not achieved, the options ²⁶ are to:

- transfer care
- treat according to the family/whanau wishes
- treat according to the family/whanau wishes and commence legal proceedings using the *parens patriae* role of the Court or relevant child protection statutes
- treat according to the clinician's wishes and leave the onus on the family/whanau to commence legal proceedings.

While the Courts are understandably reluctant to override guardian's wishes and withdraw care, there is no question that they have authority to do so under the Care of Children Act or *parens patriae* jurisdiction and there is solid precedent for doing so.

The request to cease treatment inappropriately can also be an extremely testing situation for the treating team. It must be remembered that anyone, parent or clinician, with charge of caring for someone unable to care for them self is obliged to provide the necessities of life. While consent to medical treatment is normally an essential prerequisite of any treatment, a simple withdrawal of parental consent for treatment is not legally binding if the treatment is deemed to be medically indicated and in the child's best interests. Under New Zealand and Australian law, parental rights co-exist with their responsibilities to the child. Should decisions made by the parents no longer be in the child's best interest, these decisions can be legally challenged.

The problem is that such requests often arise when the best interests of the child may not be fully clear. In this situation there is an obligation to continue treatment, in order to avoid denying the child full consideration of the issues and the opportunity for judicial review, should this prove necessary.

This should not preclude recourse to legal action in extreme cases, but such an approach can have dire costs for the family/whanau and for the relationship between the

family/whanau and treating team. A decision will usually result, but may not be presented in a way which strengthens the relationship between the family/whanau and treating team.

Management of staff during times of disagreement is also critical. It is easy for positions to polarise, with dissenting or non-compliant parents becoming stigmatised. The leadership group must ensure a climate of respect for difference of opinion, to allow relationships to be maintained sufficiently so issues can be worked through over time.

Communicating with Children

It is well recognised that children faced with a life threatening illness know they are dying before death is imminent, even if this information is not communicated to them.²⁷ Both parents and children may refrain from discussing death in an attempt to protect the other from experiencing pain and suffering, known as 'mutual pretence'.²⁸ This desire to protect their loved ones can make children vulnerable to coercion as they ignore their own wishes in an effort to avoid upsetting others.²⁹ Recent literature³⁰ suggests that parents of children who were terminally ill with a malignant disease never regretted talking to their child about death but 27% of those who did not talk with their child regretted not having had this conversation. This lament was even more pronounced in the group of parents who sensed that their child had an awareness of their imminent death. Discussing death and dying with a child is difficult for both family/whanau and the treating team yet, if done well, can enhance the time a family/whanau has together and lay the foundations for a less distressing bereavement.³¹

A child's ability to participate in decision-making is dependent on their willingness and competency, but lack of competency should not preclude their views being heard or stop them from being able to make some simple choices regarding their care including the planning of their funeral. This allows the child a degree of control and permits them to feel a part of decision-making rather than feeling disempowered or alienated. The competent adolescent should always be included in discussions about their care, unless they expressly request not to be.

Communication with a child is dependent on a number of factors, with age playing a significant role in the child's understanding of death. However, even within a defined age range this understanding can be quite variable, depending on the child's level of maturity, appreciation of illness, previous experience of death and cultural and spiritual milieu. Information should be paced according to the child and provided in an open, honest manner using appropriate resources such as books, stories and play.

Table 1 – provides a general guide to the developmental understanding of death for children within different age groupings.

Specific Issues

- **Neonatal Period**

The previously discussed factors have application in the prenatal and neonatal period. The points of contrast are, in most situations, the change in treating team from antenatal to postnatal care, intrinsic role of counselling, and differences in attachment from the older child.

The treating team can often change from the antenatal to intrapartum to neonatal stage. This requires effective cross team communication and collaboration to maintain consistency in decision-making. The obstetric and midwifery team is primarily involved during the antenatal and intrapartum phases but can be complemented by involvement of maternal fetal medicine, social work, pastoral care, and counselling; psychological and genetic. The postnatal period will see the continued input of allied health staff but a shift from the obstetric to neonatal teams. This can mean allied health staff may hold important knowledge of the family/whanau, making them key to maintaining continuity in transition.

Parents of the older infant/child have an established attachment whereas the attachment to the fetus/newborn is formative. One of the goals of care and a consideration in decision-making should, therefore, be the enhancement of attachment by providing opportunities to create memories through, amongst other things, bathing, dressing and photographs of the baby.

Decision-Makers

Adults and older children are able to choose or influence their management whereas the infant is disadvantaged in having no opportunity to form or express views concerning their care. They can be further disadvantaged by family/whanau, medical and, at times, legal uncertainty as to the way forward. This can result in the continuation of treatment under conditions in which many adults would choose to forgo aggressive treatments with consequent suffering from such treatment. Proxy decision-makers, whether family/whanau or institutional, may err on the side of requiring an unattainable level of certainty before allowing cessation of treatment. Conversely, the infant may also be disadvantaged in not having the same ability to demand ongoing care as competent adults, decisions being made for them by others who may be driven by other interests.

The treating team must always see itself as an advocate for the interests of the child and must be prepared to manage difference with the parents from this perspective. This usually entails taking time to explore and to develop consensus, but very occasionally may include court or protective action. This must, however, be coupled with respect for the role of parents as the primary advocates for their child in the majority of situations.

Most neonatal deaths occur in the intensive care environment, or under the management of a neonatal intensive care team. These units are frequently very busy, with high patient turnover and a higher number of deaths than most other paediatric units. The large number of staff involved in caring for critically ill infants and the uncertain and difficult nature of the management decisions which must be faced can lead to disagreements. These must be handled carefully if management is to continue to be driven by the welfare of the baby and family/whanau.

Perinatal issues

Many neonatal end of life decisions arise in the antenatal period, with the diagnosis of severe, perhaps lethal, abnormalities or in the context of a high risk pregnancy in which the delivery of an extremely premature or otherwise compromised infant is anticipated.

Fetal abnormality

The antenatal diagnosis of severe abnormality in the fetus is a profound disruption to a time of life that, for most, is one of happy anticipation. Feelings and beliefs concerning the fetus and the future infant are incompletely developed and must now be re-focused around the issue of the abnormality and the decisions which may have to be made. This process runs together with the evolution of grief, guilt and other strong emotions associated with the recent awareness of the fact that they are not carrying a normal child.

Decisions concerning termination of pregnancy, antenatal management and postnatal management, including the withholding of aggressive treatment, may need to be made with incomplete prognostic information and for an individual with whom a fully-formed relationship has yet to develop.

Extreme prematurity or severe illness in fetus

Threatened prematurity or severe fetal illness may arise in many different contexts, and be influenced by a large number of factors including language and cultural barriers and maternal factors. For example, maternal ill-health, previous pregnancy loss, poor antenatal care, young age and low education level can all contribute to the complexity of the situation. The margins of viability introduce new uncertainties in neonatal decision-making particularly as real doubt exists over how any one individual will tolerate ex utero life at very low gestation.

The acuity of presentation influences the decision-making process. A slowly arising event can allow sufficient time to explore the issues and plan in advance. In contrast, swift and unexpected occurrences demand rapid decisions with limited information. Family/whanau participation can be further compromised by the need to travel large distances from home, potentially leaving the pregnant woman without her normal supports for a critical period of time.

Disagreement at/around birth

The time and situational pressures inherent in decision-making around birth may create difficulty for family/whanau and staff. A quickly changing obstetric situation may preclude in-depth discussion and force decisions to be made without complete knowledge of both the family/whanau position and the clinical prognosis of the baby. The default option for most units in Australia and New Zealand is to initiate treatment and reassess while continuing discussion. This maintains options for the baby and choices for the family/whanau. However, this default option should not be seen as a commitment to maintain ongoing treatment if reassessment deems this to not be in the best interests of the infant.

In the circumstance of infants with an extremely small chance of survival it may be appropriate to not offer treatment, such as with infants born at 22 or 23 weeks gestation, particularly if in poor condition.³² There is no legal obligation to offer treatment which is not medically indicated or which is futile, although taking this step in the absence of agreement should be considered only after all avenues have been exhausted.

As gestation rises and infant condition improves, the presumption of intention to treat becomes more likely. The exact point that this shift occurs will be determined partly by local conditions. For most units in Australia and New Zealand the presumption to treat exists at 24 weeks gestation, assuming a baby born in good condition and that this is in agreement with the wishes of the family/whanau.

Relationship with teams involved

Neonatal decision-making crosses temporal and professional boundaries, in that key decisions surrounding end of life issues may have to be made before birth. This requires close collaboration between neonatal and obstetric teams as paediatric issues such as prognosis, management choices and the burden of care are intertwined with decisions about both the obstetric care of the mother and fetus and the immediate neonatal care of the baby. Similarly, babies with complex medical and surgical conditions are more than likely to be managed by multiple teams (neonatology, surgical, subspecialty), all of which have important and potentially overlapping roles.

It is important that treating teams have as much opportunity for discussion as possible and that all teams consult fully with the family/whanau. The difficulty in this situation is to avoid giving the family/whanau contradictory information. Joint consultation may be the most effective way to pursue this, but a key decision-maker and contact for the family/whanau should be identified so as to minimise the risk of “mixed messages”, major changes in approach and confusion for the family/whanau.

Some shifts will inevitably occur with new information. Antenatal counselling should accommodate this possibility and, ideally, include the paediatric staff that will be providing the postnatal care for the baby. This allows all to have a clear understanding of both medical management and parental priorities before, during and after birth.

Management plan

Antenatal Planning

This may include explicit discussion on limits of obstetric management, for example, avoiding caesarean section for an extremely premature infant or one with a severe abnormality. These decisions must be negotiated with other teams likely to be involved and clearly documented. The same applies to decisions concerning paediatric management. To avoid decisions being compromised by the pressure of labour they should be made as early as possible before labour.

Such decisions might include:

- Site of delivery – home versus hospital.
- When antenatal transfer to a tertiary centre is appropriate.
- Presence or absence of paediatric team at birth.
- People or teams to be involved with decision-making.
- Decisions on resuscitation limits
 - initiation based on gestational age or infant condition.

- use of assisted ventilation.
- use of aggressive resuscitation and stabilisation.
- Planned “trial of life” with limits around review and continuation of treatment in first hours.

Postnatal

Following birth more information is available and decisions can be reviewed and adjusted according to circumstances. This period may also involve a change of treating team and if a key person has not been identified to follow this change in team then time must be allowed for development of supportive relationships and clarification of decision-making pathways.

The majority of deaths occur in the first week of life. This is often a time of rapid clinical change but even so a need for a background in the form of a broad long term provisional plan remains. This should be reviewed at appropriate intervals, being informed by the evolving clinical situation and all changes in goals, direction or limitations of treatment documented in the medical notes. Family/whanau should be prepared, in advance, for possible changes to the plan.

• **Severe Neurological Impairment**

Children with severe neurological impairment, particularly those with cognitive disability frequently require surrogate decision-makers. This is usually the child’s parents and they often face making these decisions in an environment of personal distress, prognostic uncertainty, and having to evaluate what is in their child’s best interest based on the subjective concept of quality of life.

A collaborative approach to decision-making can alleviate some of the family/whanau burden. They are unlikely to have had personal experience of the situation and are endeavouring to make decisions based on forecasting their child’s response. This is made even more difficult by their emotional turmoil and awareness that any decision made will be carried by them for the rest of their lives. The clinician and treating team can provide their knowledge, experience, and relatively lower level of emotional involvement with the child to help the family/whanau weigh values, beliefs and educate expectations to achieve the best outcome for the child.³³

However, even the treating team have the dilemma of prognostic uncertainty. Many of the conditions, whether acute or chronic, require decisions to be made in the absence of a clear outlook particularly as improvements in medical and pharmacological management are helping children live longer. This is often brought into sharpest relief by the scenario of determining neurodevelopmental outcome in the first weeks after an acute insult to a child.

It is not uncommon for decision-making in children with severe neurological impairment to require consideration of, or even hinge on, the intangible and subjective concept quality of life. This has been highlighted in British law when the Court of Appeal accepted that it was lawful to withdraw life-prolonging treatment for a child when the quality of life would be intolerable. In coming to this decision the court recognised that a quality of life which could be considered intolerable to an able-bodied person would not necessarily be unacceptable to a child who had been born disabled.⁷

Impairment is not incompatible with a life of quality and people with severe impairment describe a life of high quality, which they are happy to be living. It comes down to individual perception so what is tolerable for one person may be intolerable for another. It is particularly difficult to assess the acceptability of a disability for a child but a disability may not necessarily be viewed negatively, provided adequate support is available. However, a degree of impairment exists that the majority of people would perceive as intolerable. This level often includes a loss of awareness and inability to interact. It is important to remember that this burden is not only for the child but also the family/whanau.⁷

It should also be recognised that individual, family/whanau and clinician perception of the child's quality of life can be influenced by the presence of symptoms such as pain, seizures and excessive secretions. All of these symptoms can be amenable to medical management but satisfactory control can be hampered by unacceptable adverse effects and, at times, symptoms can be intractable in spite of a rigorous approach.

The decision-making process for the care of children with severe neurological impairment should be a collaborative effort between the treating team and family/whanau with their values and desires being at the centre. It needs to be recognised that it can be difficult to present an accurate prediction for quality of life even after a thorough search for prognostic features.

- **Emergency Treatment**

Unexpected emergencies often lead to escalation of care beyond what may have been anticipated or discussed. Ideally, such crises should be anticipated and a care plan prepared in advance with the family/whanau. It may then be appropriate to limit treatment at the time of deterioration.

The main disadvantage of this approach is that deteriorations are inherently unpredictable. It may be psychologically easier for the treating team and family/whanau to 'let go' at the time of such an episode but the unpredictability creates the risk of a child dying unsupported by their family/whanau. It can also deny the family/whanau an opportunity to deal with the fact that their child is dying before it occurs and to achieve any final goals they may have had for their child.

When limitation of treatment has not been discussed or when a crisis arises in a previously healthy child, the goal of management must be to stabilise the child pending further discussion with the family/whanau. The nature of such situations is inherently complex and uncertain with both the family/whanau and treating team potentially having only partial knowledge of the medical situation and its prognosis.

Given this, the fundamental priority is the interests of the child. This is likely to be best served by active treatment in the first instance. Decisions on management can then be discussed and made once prognosis becomes clearer with further investigation. Should disagreement with the family/whanau arise in this situation, the presumption should favour treatment while uncertainty is not resolved.

Appendix 1 – Guide to Disclosing Information

1. Use a quiet, private location.
2. Early involvement of a senior person who, ideally, is familiar to the family/whanau.
 - Person must have a clear understanding of the medical and family/whanau issues and be able to answer any questions that may arise.
 - This does not have to be a doctor and could be, for example, an experienced nurse or social worker.
3. Prepare the family/whanau by giving an indication of the interview's seriousness.
4. If at all possible, both parents should attend and hear any significant news before other family/whanau members.
 - It may be appropriate to involve extended family/whanau or friends.
5. Provide appropriate support from somebody NOT involved with giving information.
 - This person can be established from the family/whanau.
6. Provide an interpreter if there is the slightest doubt about the ability of all key members of the family/whanau to understand English.
7. Parental knowledge/understanding must NEVER be taken for granted.
 - Provide a summary of the child's situation – it is easier to deal with complex issues when everyone starts with similar knowledge.
 - The family/whanau should be given an early opportunity to speak so their understanding of the situation is established and their concerns heard.³⁴
8. Present information simply and plainly, maintaining a focus on core issues.
9. If feasible, plan for time and repeated interviews to allow for the normal delay in assimilating and understanding distressing news.
10. Decisions should not be rushed, unless clinical circumstances dictate otherwise.

Table 1 – Children’s Understanding of Death

Child’s Age	Understanding	Response
Infants (0-1yr)	No concept of death. Sensitive to the emotions of carers.	Maintain normal routines. Provide comfort/comfort items/cuddles. Calm and gentle approach. Avoid separation.
Toddlers (1-3yr)	As above. Capable of true sadness. Can process grief if adequately supported.	As above. Curious – require adults to be open and emotionally accessible. Simple, honest answers to any questions asked.
Preschool (3-5yr)	Death viewed as: <ul style="list-style-type: none"> • Temporary or reversible – magical thinking present. • Accidental rather than inevitable. • Associated with specific circumstances i.e. becoming old. Assume they will not die.	As above. Focus support on reassurance, maintaining emotional security and encourage play. Very literal – use simple, clear language when explaining death as confused by euphemisms such as “going to sleep”. Explanations may need to be repeated on several occasions.
School Aged (5-10yr)	See death as irreversible but avoidable. True meaning of death understood with increasing age but influenced by: <ul style="list-style-type: none"> • Family/whanau, cultural and religious beliefs. • Their experience of loss. 	As above. Use words that describe feelings. Explain death as part of life – use examples in nature.
Early Adolescent (10-13yr)	Death seen as an inevitable process associated with the irreversible cessation of all body functions. Fears attached to death are those of pain and mutilation. Tend to focus on events immediately surrounding illness, death and burial. Discussions about death may be avoided for fear of upsetting parents.	As above. Provide time to talk – may discuss feelings more freely with friends, teachers or other adults. Sadness and anxiety may be expressed by poor school performance, irritability or social withdrawal. Avoid expecting adult behaviour.
Middle Adolescent (13-16yr) ³⁵	Death accepted as part of life. May lack emotional capacity to deal with, and talk about death. Illness often conflicts with normal pattern of increasing independence. Have a sense of what they will miss in their lives and may feel they are letting others down by not recovering from their illness.	As above. Talk to them about grief. Acknowledge emotions they may be feeling. Provide opportunity to interact with other adolescents with similar illnesses. Potential for risk taking behaviour to escape feelings/reality and as a source of comfort.
Older Adolescent (16-18yr) ³⁵	As above. Should be allowed to: <ul style="list-style-type: none"> • Express their preferences about end of life care. • Be a part of decision-making process including place and situation of their death. Interested in how they will be remembered.	As above. Respect rights and wishes. Provide opportunity to draw, write poems, or leave some memories behind for friends and family/whanau.

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