

CLINICAL PRACTICE GUIDELINES

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WITHHOLDING AND WITHDRAWING OF LIFE SUPPORT IN CHILDREN



MINISTRY OF HEALTH MALAYSIA



ACADEMY OF MEDICINE

Statement of Intent

This clinical practice guideline is meant to be a guide for clinical practice, based on the best available evidence at the time of development. Adherence to these guidelines may not necessarily ensure the best outcome in every case. Every health care provider is responsible for the management of his/her unique patient based on the clinical picture presented by the patient and the management options available locally.

Review of the Guidelines

This guideline was issued in 2005 and will be reviewed if new evidence becomes available.

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GUIDELINE DEVELOPMENT AND OBJECTIVES

Guideline Development

The working group for the development of this guideline comprised of paediatricians, a paediatric anaesthesiologist and a legal advisor from the Ministry of Health and the Ministry of Education, as well as a legal personnel from the private sector. This guideline is based on the findings of a systematic review of current medical literature, taking into consideration local paediatric practices. The grading of evidence is based on a modified version of that suggested by the Catalonian Agency for Health Technology Assessment & Research, Spain. The draft guidelines were sent to various paediatricians -for comment and feedback. These guidelines have also been presented to the Technical Advisory Committee for Clinical Practice Guidelines and the Health Technology Assessment and Clinical Practice Guidelines Council, Ministry of Health Malaysia for review and approval.

Objectives

The aim of this guideline is to aid paediatricians and intensivists in clinical decision making by providing well-balanced evidence based information and expert advice on management of withholding and withdrawing of life support in children.

Clinical Questions

The clinical questions for this guidelines are:

- (i) When should withholding or withdrawal of life support be considered in children?
- (ii) What are the legal implications of withholding or withdrawal of life support?
- (iii) What are the economic implications of withholding or withdrawal of life support?
- (iv) How should withholding or withdrawal of life support be carried out?

Target Population

This guideline is applicable to children under the age of 18 years old who are critically ill and require life support or are on life support.

Target Group

This guideline is meant for all healthcare professionals who are involved in providing clinical management of withholding and withdrawing of life support in children.

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CLINICAL PRACTICE GUIDELINES ON WITHHOLDING AND WITHDRAWING OF LIFE SUPPORT IN CHILDREN

1. INTRODUCTION

Technological advances in modern medicine have had a great impact on the care of critically ill patients, saving many children's lives, but also leaving others with chronic diseases and disabilities. The increased ability to sustain life with intensive care may lead, unfortunately, sometimes only to prolonging suffering when treatment is unsuccessful, and prolonging the dying process, attached to technology, instead of dying with dignity in the company of loved ones. Thus, with these new technologies also comes the responsibility to understand how, when, and why these technologies are applied, and when technology should not be used or withdrawn.

Professionals have a duty to act in their patients' best interests, to sustain life and restore health to an acceptable standard (Chantler & Doyal, 2000, *Level 9*). However, it is important both from an ethical as well as an economic viewpoint, for these professionals to recognise the limits of unnecessary prolongation of life. Furthermore, recognition that resources are finite, limit the provision of care that is deemed futile.

The decision by a doctor to withhold or withdraw treatment, but not care, (please see Appendix 1 for definition of terms) from a patient may result in a serious conflict with a parent who insists otherwise. However, this may be ethically justifiable and legally defensible under certain circumstances, since doctors are morally obliged to question if providing treatment is inconsistent with his professional ethics. The decision to withhold or withdraw treatment can be made on the basis that treatment is contrary to the child's best interests, disproportionately burdensome, futile, or even harmful (Larcher & Hird 2002, *Level 9*; Schneiderman et al, 1996, *Level 9*).

2. METHODOLOGY

A systematic search of the literature using PubMed, Proquest, Ovid, and Ebsco was carried out. The key words used included *withdrawal, withholding, limitation, life-sustaining therapy, life support, treatment, children, neonate, intensive care, paediatric intensive care, ethical, cost, and financial implication*, used singly or in combination. The Cochrane Database of Systematic Reviews and Evidence Based Medicine Database of Abstracts of Reviews (DARE) were also searched. Additional literature search was carried out using the words *nutrition* and *hydration*.

3. REASONS FOR WITHDRAWAL/WITHOLDING LIFE SUPPORT

3.1. Neonates

Decisions relating to the withholding and withdrawal of life-sustaining medical treatments are a necessary part of a neonatal unit's practice (Larcher & Hird 2002, *Level 9*). Many decisions regarding life support call for the use of '**best interests**' **standard**, involving weighing the benefits and burdens of life-sustaining medical treatment (please see Appendix 1 for the range of LSMT).

The benefits include the following:

- Prolongation of life (understanding that the continuation of biological existence without consciousness may not be a benefit)
- Improved quality of life (including reduction of pain or disability)
- Increased physical pleasure, emotional enjoyment and intellectual satisfaction.

The burden of life sustaining medical treatment (LSMT) may include the following

- Intractable pain
- Irremediable disability or helplessness
- Emotional, psychosocial and economic suffering
- Invasive and/or inhumane interventions that severely detract from the patient's *quality of life* (i.e. experience of life as viewed by the patient, and not *social worth* as judged by others) (Meisel, 1989, *Level 9*)

3.1.1. Labour room/ operation theatre

Cardiopulmonary resuscitation in the labour room presents clinicians with significant ethical issues. The resuscitation of critically ill infants is a difficult choice and decision of whether to resuscitate or not must often be made rapidly. Generally, it is recommended that if there is any doubt, resuscitative efforts should be provided, since it allows time for increased prognostic certainty and opportunity for joint decision-making (Meadow et al, 1996, *Level 8*).

Resuscitation may be inappropriate for the following:

- Extremely low birth weight - gestation <23 weeks or birth weight <400gm
- Neonate with severe congenital defects e.g. anencephaly
- Severe perinatal asphyxia e.g. persistent asystole for >15 min. (Niermeyer et al 2000 *Level 9*; Goldsmith et al, 1996, *Level 8*)

3.1.2. Neonatal Intensive Care Units

In UK, withdrawal of treatment accounts for up to 30% of neonatal intensive care deaths (Wall & Partridge, 1997, *Level 8*). In USA, according to the *Baby Doe regulations* (1985) doctors must treat all infants with life-threatening conditions, except in the following situations (Lantos et al 1994, *Level 8*):

- Infant is chronically and irreversibly comatose

- Provision of treatment would merely prolong dying, not be effective in relieving or correcting all the infant's life-threatening conditions, or otherwise be futile in terms of survival of the infant (Lantos et al, 1994, *Level 8*)
- Treatment under such circumstances would be inhumane (Department of Health and Human Services, 1985, *Level 9*)

Decisions to withhold or withdraw life-sustaining medical treatment have to be based on careful assessments of the infant's clinical condition. The long-term implications of clinical findings such as the following:

- bilateral cerebral intraparenchymal haemorrhage
- diffuse periventricular leukomalacia
- severe perinatal asphyxia with grade III hypoxic-ischaemic encephalopathy have been established as having poor prognosis, the neurodevelopmental outlook in many other situations is often not clear (Larcher & Hird 2002, *Level 9*). Thus, while reasons for withholding or withdrawal may vary, these will fall into the following 2 categories:

a. No chance for survival (Cook & Watchko, 1996, *Level 8*; Caniano et al 1995, *Level 8*) or **continued treatment futile in the face of imminent death** (Cuttini et al 2000, *Level 8*; Caniano et al 1995, *Level 8*)

- Limited life expectancy
 - End of treatment line-**death inevitable** (Kelly et al 1994, *Level 8*)
 - Lesion **incompatible with life** (Kelly et al 1994, *Level 8*)
 - **Poor chance of survival** (Hazebroek et al 1993, *Level 8*; Whitelaw, 1986, *Level 8*)
- Inevitable dependency on life-sustaining treatment
 - Lesion will **not allow meaningful survival** (Kelly et al 1994, *Level 8*) or **poor prognosis for later life** (Hazebroek et al 1993, *Level 8*)
- Impossibility that the infant would ever go home (daCosta et al 2002, *Level 8*; Van der Heide et al 1998, *Level 9*; Wall & Partridge 1997, *Level 8*; Van der Heide et al. 1997, de Leeuw et al 1996, *Level 8*; *Level 8*; Lantos et al 1994, *Level 8*)

b. Quality of life issues (Cook & Watchko et al 1996, *Level 8*; Hazebroek et al 1993, *Level 8*)

Expected poor quality of life/**severe disabilities or severely deforming and incapacitating condition** with little or no hope of achieving meaningful 'humanhood' (Cuttini et al 1999, *Level 9*; Fost 1999, *Level 9*)

- **Severe brain damage** when death may be preferable to life (Kelly et al 1994, *Level 8*)
- **No prospects for improvement**

- **A high degree of suffering or unnecessary suffering** - neonate's **burden of pain and suffering** with treatment does not outweigh the benefits of life even if the infant is not in a terminal state (Cuttini et al 1999, *Level 8*; Ryan et al 1993, *Level 8*)
- **An expected poor developmental outcome** (Fost 1999, *Level 9*)
- **Poor social support for disabled** (Fost 1999, *Level 9*)
- **A very high burden of treatment** (Van der Heide et al 1998, *Level 9*; Wall & Partridge 1997; *Level 8*; Whitelaw 1996, *Level 9*; Doyal & Wilsher. 1994, *Level 9*; Lantos et al. 1994, *Level 8*; Airede 1991, *Level 8*)

Causes of these may include the following:

- Extremely Low Birth Weight infants
 - gestational age <26 weeks with intrauterine infection
 - gestational age <26 weeks with severe complications
- Prematurity with severe complications
- Respiratory distress syndrome with complications
- Severe intracranial haemorrhage
- Perinatal asphyxia with hypoxic ischaemic encephalopathy
- Severe intractable septicaemia
- Intractable respiratory failure
- Severe/multiple congenital malformations

3.1.3. Disorders or Specific Structural Defects Incompatible with Life

- Cephalic disorders
 - Hydranencephaly
 - Anencephaly
 - Holoprosencephaly
 - Sirenomelia
- Genetic defects
 - 13 trisomy syndrome
 - 18 trisomy syndrome
 - Triploidy
- Short-limb dwarfing syndromes
 - Achondrogenesis-hypochondrogenesis
 - Type II achondrogenesis-hypochondrogenesis
 - Fibrochondrogenesis
 - Atelosteogenesis
 - Short-rib polydactyly syndrome, Saldinnoonan type
 - Thanatophoric dysplasia
 - Osteogenesis imperfecta type II

- Miscellaneous syndromes
 - Lethal multiple pterygium syndrome
 - Neu-Laxova syndrome
 - Meckel-Gruber syndromes (Goldsmith et al 1996, *Level 8*)

3.2. CHILDREN

Most deaths (65%) occur in paediatric intensive care unit (PICU), and these deaths are mostly in children less than one year, with up to 50% having underlying chronic disease (Martinot et al, 1995, *Level 8*; Levetown et al; 1994, *Level 7*; Vernon et al, 1993, *Level 8*; Mink & Pollack, 1992)

3.2.1. Medical factors

- Clinical assessments should be based on whether each potentially available treatment would benefit the patient, taking into account the residual effect of any remaining medication or treatment on the patient.
- Treatment decisions must be based on the best available clinical evidence - guidelines should be consulted as part of the clinical assessment (where available), additional advice being sought where necessary.
- Active treatment may be withheld or withdrawn, if unable to achieve its intended clinical goal, or the patient's imminent death is inevitable,
- Where the patient has an existing condition, a management plan should be formulated to anticipate progression of the disorder or cardiac arrest
- Where the patient presents with a sudden or unexpected medical event, the condition should be stabilized to allow proper assessment

3.2.2. Futility of care

With patient autonomy, some patients and their families claim the right to receive any aggressive high tech medical interventions on a chance of improving survival, even if the medical provider judges the treatment to be futile.

Futility refers to whether treatment will benefit an individual patient (Schneiderman et al, 1996, *Level 9*), and is an increasingly common justification for refusing to provide treatment requested (Prendergast 1995, *Level 9*). Nelson (1995, *Level 9*) suggest that *futile* be restricted to judgments of "strict futility" and to use *disproportionate burden* when a doctor judges that the burden of continued treatment for the child far outweighs any expected benefit.

Strict futility or *physiologic futility* is when a certain treatment fails to preserve a physiologic function vital for survival, resulting in imminent death e.g. the administration of vasopressors that fails to maintain an adequate blood pressure following a cardiac arrest. The doctor is not ethically or legally bound to offer or provide it, regardless of patient or parental wishes.

Disproportionate burden involves value judgment about the benefits and burdens of continued treatment. Treatment will not benefit the patient, causes pain and suffering, and does not contribute to restoring acceptable quality of life, although the patient may survive for years. The doctor may be justified in refusing to provide that treatment despite parental disagreement, but foregoing treatment should not be the doctor's decision alone unless death is imminent. However, it has been shown that few paediatric intensive care beds were used for futile care (Goh & Mok, 2001, *Level 8*; Sachdeva et al, 1996, *Level 8*).

4. INTENSIVE CARE IN THE CRITICALLY ILL CHILD

Injudicious application of intensive care i.e. mechanical ventilation, dialysis and cardiopulmonary resuscitation (CPR) may create a clinical scenario in which a patient can be maintained alive in an ICU setting with burdensome therapy, never entering a conscious state, survive and be discharged home with an unacceptable quality of life, or when therapy is failing, deprive another patient who has a chance of a more meaningful survival if given access to the ICU.

Some questions one should consider when making decisions on whether to admit a critically ill patient with cancer to the ICU or to institute CPR are:

1. Is there a chance of the disease being cured, controlled or put into remission, and a meaningful life?
2. Is autonomy of patient respected?
3. Is there distributive justice? Patient with the best chance of benefiting from intensive therapy should receive priority for admission.

Australian Classification system for cancer provides a framework to discuss goals of care relative to cancer status (Meadow et al 1996, *Level 9*)

As healthcare costs continue to increase economic analysis will be necessary to guide resource allocation decisions. Cost effectiveness analysis is the most popular and it evaluates the effectiveness of one treatment versus another. In end-of-life issues the perspective needs to be broad and include all those who gain as well as those who pay (ATS Bioethics Task Force 1997; *Level 9*).

The value of the health consequence is usually reported as a quality of adjusted life year (QALY). QALY is simply the weighted average of the value of a health related quality of life where death is 0 and optimum health is 1. This assumption may not hold true when considering terminally ill patients.

5. LEGAL IMPLICATIONS

Legally and ethically, the decision to treat or not to treat is justifiable only when it is in the best interests of the child (please see Appendix 2 for details of rights of a child). However, perceptions about the child's best interest may differ, and 'best interest' may not be synonymous with prolongation of life.

Those with parental responsibility for a child are legally and morally entitled to give or withhold consent to treatment, unless they conflict seriously with the interpretation of those providing care in the child's best interests. According to the Child Act 2001, parents can lose their rights and the child taken into protection, if parents object to the child's needs to be examined, investigated or treated for the purpose of restoring or preserving his health. Although a child under 18 years of age with a sufficient level of competence and understanding can give valid consent to treatment, he/she however cannot refuse to have life saving treatment.

In general, doctors judge the clinical factors, and parents determine best interests of the child. If there is a disagreement that cannot be resolved, a Court may determine whether the provision of life-prolonging treatment would benefit the child.

6. ECONOMIC IMPLICATIONS

6.1. Cost Implications of End-of-Life Care

It has been shown that end-of-life care consumes 10-12% of all health care expenditures. For terminally ill patients, significant cost savings can be achieved with the use of hospice, and the lower use of high technology interventions.

Initiation of renal support such as dialysis as well as CPR in critically ill patients has been found not to be cost effective. The cost effectiveness of palliative therapies is difficult to calculate since there is no good measure for valuing the quality of death.

6.2. Care of Extremely Low Birth Weight Babies

Extremely low birth weight (ELBW) babies require expensive and scarce resources, having poor prognosis for survival should they require intensive care. Intensive care is costly and outcomes are often uncertain, and hence, rationing of these resources is inevitable. Neonatal intensive care mortality decreases as the birth weight increases, so that most NICU deaths occur during the first few days leaving a relatively healthier population with greater likelihood of survival (Meadow et al 1996, Level 9). Since premature ELBW babies result in early deaths, the policy is to initiate treatment on most babies to see who will do well and who will develop life-threatening complications (Peabody 1996, Level 9). However, many studies have shown aggressive

treatment and surgical management of ELBW babies has poor outcome and is not cost effective (Young & Stevenenson 1990, *Level 9*; Civetta 1996, *Level 9*; ATS Bioethics Task Force 1997, *Level 9*). Treating them over-vigorously violates the moral principles of non-maleficence and distributive justice. Similarly, failing to treat vigorously due to concerns regarding non-maleficence and distributive justice could violate the principle of patient-centered beneficence. Distributive justice compels the doctor to allocate finite resources equitably (Young & Stevenson 1990, *Level 9*; Pronovost & Angus 2001, *Level 9*).

7. WITHDRAWAL OR WITHHOLDING LIFE SUPPORT IN PRACTICE

The practical issues for withdrawal in neonates and children are similar in many respects and will be discussed together, unless indicated otherwise! The term “child” designates both neonates and children.

7.1 The decision to withdraw life support

In principle the decision on when to withdraw life support is made by the attending consultant paediatrician with the assistance of the whole team (colleagues, medical officers, nursing personnel) and in consultation with parents.

7.2 Pre-Withdrawal Preparation

1. It is important that the decision to withdraw life support is a team effort in which the parents are fully involved. The decision should first be discussed with personnel involved in the care of the child. It should then be discussed with the parents before a final decision is made.
2. If a parent (e.g. mother post LSCS) has not seen the child since admission, attempts should be made for that parent to see the child before the actual withdrawal is done.
3. For continuity and trust, it is important that the attending team - consultant paediatrician, medical officer and nurse be present to see the parents through the whole process: pre-withdrawal, withdrawal and post-withdrawal counseling.
4. The attending consultant paediatrician (or most senior member of the team), medical officer and nurse should discuss the following with the parents:
 - a. The timing of the procedure - the date and time of the actual withdrawal should be decided by the parents (within reasonable limits).
 - b. What the procedure entails - care should be taken to indicate how long the breathing might continue, that the child may have gasping respiration, that sedation may be used if the child in anyway appears to suffer.

- c. Who, if any, of the family members will be present with the child, during the preparation of the child, during the switching off, and after switching off. It may be meaningful in the grieving process for siblings and grandparents to be present.
 - d. Religious needs - at times parents may request a religious person to be present to pray for the child, or this spiritual role can be undertaken by anyone else like a staff member.
5. Establish the parents' preferences for the following:
- a. Naming the child.
 - b. Photographs - parents may wish to take photographs of the child (these can be taken at the time of withdrawal when the child is fully clothed or earlier).
 - c. Hand and footprints, hair clippings etc (may be taken by the parents later if they prefer).
 - d. Holding the child during the dying process.
 - e. Clothing the child.
 - f. Post-mortem

7.3 Withdrawal Procedure

1. The attending nurse prepares an empty cot, child's clothes, any prescribed sedation or analgesia. Photograph child before stopping ventilator if desired.
2. Place screens around child and ask visitors to other babies to leave the ventilation area.
3. The attending nurse prepares the child in the following manner:
 - a. Removing all invasive lines except the endotracheal tube. Just prior to this it may be wise to give sedation (e.g. a morphine purge to limit the trauma of gasping). Alternatively, it is possible to keep one heparinised IV line in case of need for sedation.
 - b. Cleaning any blood or fluid stains on skin if necessary.
 - c. Changing nappy and dressing child in selected clothes.
4. Parents and designated family members can be present for this process or be waiting in a designated room.
5. Allow for time to pray – formal prayers by person designated by parents or by ward staff.
6. Designated person (preferably attending paediatrician or medical officer) to stop ventilator and withdraw endotracheal tube.

7. The attending nurse to hand over the child to parents and family. At times it may be appropriate to wrap the newborn in a shawl so as to cover birth defects and present the child as best as possible. Place in cot and wheel to a private room with family (this may be a designated “bereavement room”, a counselling room or the room used for breast milk expression)
8. The attending nurse and doctor should do the following during the dying process:
 - a. Encourage parents to hold the child.
 - b. Standby with parents if requested but it is generally preferred to allow them to be alone with child during the dying process.
 - c. Check child and parents intermittently.
 - d. Leave family with child for as long as they want but not for too long a period.
 - e. Provide tissues and refreshments as necessary.

7.4 Post-Withdrawal Management (After Death)

1. The attending nurse and doctor should express sympathy to parents. Some physical contact may be meaningful (e.g. a hug or holding the hand).
2. The attending doctor to certify the death.
3. The attending nurse should explain the process of releasing the child's dead body.
4. Before the parents leave, the attending doctor should arrange a one week appointment for parents with the attending consultant paediatrician (or neonatologist) to facilitate the grieving process. The primary focus of the follow- up is to help parents with the decision for withdrawal and assess/discuss any guilt feelings. In addition, there may be a need to re-discuss the diagnosis or provide more information from tests.

7.5 Emotional Health of Staff

The withdrawal of life support is an emotionally traumatic experience. This is true even for local paediatric departments which have been practising this for years. It is important that the nursing staff and doctors caring for these children have opportunities to express their own pain and grief. This can be done informally or having formal staff meetings for the purpose.

7. REFERENCES

- Airede KI (1991). Should we resuscitate? Ethical dilemmas. *Ann Trop Paediatr.*; 11(2):169-74.
- American Academy of Pediatrics Committee on Bioethics: Guidelines on foregoing life-sustaining medical treatment (1994). *Pediatrics.* Mar; 93(3):532-6.
- ATS Bioethics Task Force (1997). Fair allocation of intensive care unit resources. *Am. J Respir Crit Care Med*, 156:1282–1301
- Caniano DA, Hazebroek FW, DenBesten KE, Tibboel D (1995). End-of-life decisions for surgical neonates: experience in The Netherlands and United States. *J Pediatr Surg.* Oct;30(10):1420-4.
- Chantler C, Doyal L. Medical ethics; the duties of care in principle and practice. In Powers M, Harris (eds). *Clinical Negligence* London: Butterworths 2000
- Child Act 2001 (Act 611); Part I Section 2(1)
- Civetta, Joseph (1996). Another point of view. Futile care or caregiver frustration? A practical approach, *Critical Care Medicine* Vol. 24 Number 2 February
- Convention on the Rights of the Child 1989. Adopted by the General Assembly of the United Nations on 20th November 1989; Article 1
- Cook LA, Watchko JF (1996). Decision making for the critically ill neonate near the end of life. *J Perinatol.* Mar-Apr;16(2 Pt 1):133-6.
- Cuttini M, Rebagliato M, Bortoli P, Hansen G, de Leeuw R, Lenoir S, Persson J, Reid M, Schroell M, de Vonderweid U, Kaminski M, Lenard H, Orzalesi M, Saracci R (1999). Parental visiting, communication, and participation in ethical decisions: a comparison of neonatal unit policies in Europe. *Arch Dis Child Fetal Neonatal Ed.* Sep; 81(2):F84-91.
- Cuttini M, Nadai M, Kaminski M, Hansen G, de Leeuw R, Lenoir S, Persson J, Rebagliato M, Reid M, de Vonderweid U, Lenard HG, Orzalesi M, Saracci R (2000). End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries. EURONIC Study Group. *Lancet.* Jun 17; 355(9221):2112-8.
- da Costa DE, Ghazal H, Al Khusaiby S (2002). Do Not Resuscitate orders and ethical decisions in a neonatal intensive care unit in a Muslim community. *Arch Dis Child Fetal Neonatal Ed.* Mar; 86(2):F115-9.

de Leeuw R, de Beaufort AJ, de Kleine MJ, van Harrewijn K, Kollee LA (1996). Foregoing intensive care treatment in newborn infants with extremely poor prognosis. A study in four neonatal intensive care units in The Netherlands. *J Pediatr*; 129 (5):661-666

Department of Health and Human Services. Child abuse and neglect prevention and treatment program: Final rule. Federal Register. 1985; 50:1478-92

Doyal L, Wilsher D (1994). Towards guidelines for withholding and withdrawal of life prolonging treatment in neonatal medicine. *Arch Dis Child Fetal Neonatal Ed*. Jan; 70(1):F66-70.

Fost N (1999). Decisions regarding treatment of seriously ill newborns. *JAMA*. Jun 2; 281(21):2041-2043

Goh AY, Mok Q (2001). Identifying futility in a paediatric critical care setting: a prospective observational study. *Arch Dis Child*. Mar; 84(3):265-8

Goh AY, Lum LCS, Chan PWK, Bakar F, Chong BO (1999). Withdrawal and limitation of life support in paediatric intensive care. *Arch Dis Child*; 80:424-428

Goldsmith JP, Ginsberg HG, McGettigan MC (1996). Ethical decisions in the delivery room. *Clin Perinatol*. Sep; 23(3):529-550

Hazebroek FW, Tibboel D, Mourik M, Bos AP, Molenaar JC (1993). Withholding and withdrawal of life support from surgical neonates with life-threatening congenital anomalies. *J Pediatr Surg*. Sep; 28(9):1093-1097

Kelly NP, Rowley SR, Harding JE (1994). Death in neonatal intensive care. *J Paediatr Child Health*. Oct; 30(5):419-422

Lantos JD, Tyson JE, Allen A, Frader J, Hack M, Korones S, Merenstein G, Paneth N, Poland RL, Saigal S, et al(1994). Withholding and withdrawing life-sustaining treatment in neonatal intensive care: issues for the 1990s. *Arch Dis Child Fetal Neonatal Ed*. Nov; 71(3):F218-223.

Larcher V, Hird MF (2002). Withholding and withdrawing neonatal intensive care. *Current Pediatrics*; 12: 470-475

Levetown M, Pollack MM, Cuerdon TT, Ruttimann UE, Glover JJ (1994). Limitations and withdrawals of medical intervention in pediatric critical care. *JAMA*. Oct 26;272(16):1271-1275

Maillet JO, Potter RL, Heller L (2002). Position of the American Dietetic Association: ethical and legal issues in nutrition, hydration, and feeding. *J Am Diet Assoc*. May;102(5):716-26.

Martinot A, Lejeune C, Hue V, Fourier C, Beyaert C, Diependaele JF, Deschildre A, Leclerc F (1995). [Modality and causes of 259 deaths in a pediatric intensive care unit] *Arch Pediatr*. Aug;2(8):735-41. French.

Meadow W, Lantos JD, Mokalla M, Reimshisel T (1996). Distributive justice across generations. Epidemiology of ICU care for the very young and the very old. *Clin Perinatol*. Sep; 23(3):597-608.

Meisel A (1989). The care of the dying: a symposium on the case of Betty Wright – Refusing treatment, refusing to talk, and refusing to let go: on whose terms will death occur? *Law Med Health Care*. Fall; 17(3):221-226.

Mink RB, Pollack MM (1992). Resuscitation and withdrawal of therapy in pediatric intensive care. *Pediatrics*. May; 89(5):961-3

Nelson LJ, Rushton CH, Cranford RE, Nelson RM, Glover JJ, Truog RD (1995). Forgoing medically provided nutrition and hydration in paediatrics patients. *J Law Med Ethics*; 23: 33-46.

Niermeyer S, Kattwinkel J, Van Reempts P, Nadkarni V, Phillips B, Zideman D, Azzopardi D, Berg R, Boyle D, Boyle R, Burchfield D, Carlo W, Chameides L, Denson S, Fallat M, Gerardi M, Gunn A, Hazinski MF, Keenan W, Knaebel S, Milner A, Perlman J, Saugstad OD, Schleien C, Solimano A, Speer M, Toce S, Wiswell T, Zaritsky A (2000). International Guidelines for Neonatal Resuscitation: An excerpt from the Guidelines 2000 for Cardiopulmonary Resuscitation and Emergency Cardiovascular. Contributors and Reviewers for the Neonatal Resuscitation Guidelines. *Pediatrics*. Sep; 106(3):E29.

Peabody JL, Martin GI (1996). From how small is too small to how much is too much. *Clinics in Perinatology*; Sep: 23(3): 473-489

Prendergast TJ (1995). Futility and the common cold. How requests for antibiotics can illuminate care at the end of life. *Chest*; 107 (3):836-844

Pronovost P, Angus DC (2001). Economics of end-of-life care in the intensive care unit. *Crit Care Med*. Feb; 29(2 Suppl):N46-51

Report of Special Task Force (1987). Guidelines for the determination of brain death in children. American Academy of Pediatrics Task Force on Brain Death in Children. *Pediatrics*. Aug; 80(2):298-300.

Ryan CA, Byrne P, Kuhn S, Tyebkhan J (1993). No resuscitation and withdrawal of therapy in a neonatal and a pediatric intensive care unit in Canada. *J Pediatr*. Oct; 123(4):534-8.

Sachdeva RC, Jefferson LS, Coss-Bu J, Brody BA (1996). Resource consumption and the extent of futile care among patients in a pediatric intensive care unit setting. *J Pediatr.* Jun; 128(6):742-747.

Schneiderman LJ, Jecker NS, Jonsen AR (1996). Medical futility: its meaning and ethical implications. *Ann Intern Med.* Jun 15; 112(12):949-54

Truog RD, Cist AF, Brackett SE, Burns JP, Curley MA, Danis M, DeVita MA, Rosenbaum SH, Rothenberg DM, Sprung CL, Webb SA, Wlody GS, Hurford WE (2001). Recommendations for end-of-life care in the intensive care unit: The Ethics Committee of the Society of Critical Care Medicine. *Crit Care Med.* Dec; 29(12):2332-2348

Van der Heide A, van der Maas PJ, van der Wal G, de Graaff CL, Kester JG, Kollee LA, de Leeuw R, Holl RA I (1997) Medical end-of-life decisions made for neonates and infants in the Netherlands. *Lancet*, 350(9073): 251-255

Van der Heide A. van der Maas PJ, van der Wal G, Kollee LA, de Leeuw R, Holl (1998). The role of parents in end-of-life decisions in neonatology: Physicians' views and practices. *Pediatrics* Mar; 101: 413-418

Vernon DD, Dean JM, Timmons OD, Banner W Jr, Allen-Webb EM (1993). Modes of death in the pediatric intensive care unit: withdrawal and limitation of supportive care. *Crit Care Med.* Nov; 21(11):1798-802

Wall SN, Partridge JC (1997). Death in the Intensive care Nursery: Physician Practice of Withdrawing and Withholding Life Support. *Pediatrics* 99:64-70

Whitelaw A (1986). Death as an option in neonatal intensive care. *Lancet.* Aug 9;2(8502):328-31.

Young EW, Stevenson DK (1990). Limiting treatment for the extremely premature, Low Birth weight infants (500 – 700g). *Am J Dis. Child.* May 144(5):549-52.

DEFINITION OF TERMS

1. **Benefit versus burden of care:** The primary goal of medical treatment is to benefit the patient by restoring and maintaining the patient's health as far as possible, maximising benefit and minimising harm. However, sometimes the course of the disease may cause health professionals and the child's family to consider whether continued treatment truly represents the best option. If treatment fails to provide a net benefit to the patient, it no longer becomes appropriate to prolong life at all costs, with no regard to its quality or the burdens of treatment. In such circumstances there is justification, ethically and legally, for withholding or withdrawing treatment. The goal of medicine should then shift to **palliative care**.
2. **Withholding and withdrawing:** The term "forgo" is synonymously used for both stopping a treatment already begun ("withdraw") as well as not starting a treatment ("withhold"). Other terms include "limitation of treatment" (Goh et al 1999). There is no important ethical or legal difference between withholding or withdrawing treatment when making decisions about an individual patient (AAP guidelines 1994). Yet, many health care professionals, as well as families, feel an emotional difference between the two, largely due to the impression that withdrawing treatment can be interpreted as "giving up on the patient". Some health professionals may be reluctant to start treatment in the mistaken belief that once started the treatment cannot be withdrawn. Treatment should never be withheld, especially when there is a chance the patient may benefit, simply because withholding is considered easier than withdrawing. When great uncertainty prevails, a better course would be to initiate treatment to ascertain whether it is able to benefit the patient, and subsequently withdraw it if it proves unhelpful.
3. **Life-sustaining medical treatment (LSMT):** Other terms commonly used include "life prolonging treatment" and "life support". It encompasses ALL interventions that may prolong the life of the patient and postpone death. There is evidence that if these interventions are withdrawn or withheld, death usually ensues (Goh et al, 1999; and Wall et al, 1997) There is no difference between "extraordinary" (technically demanding and often scarce) and "ordinary" interventions. However, in reality, health care professionals have many preferences and biases regarding the type and order of withdrawal of such treatment. In light of these subconscious biases, it is useful to review the wide range of LSMT and work towards an approach focusing on the unique situation and needs of the patient rather than physician preferences.

Table 1 Illustrates the range of LSMTs that may be withheld or withdrawn
(Recommendations for end of life care, Troug et al, 2001)

Therapeutic goal	Therapy
Circulatory haemostasis	Cardiopulmonary resuscitation (CPR) Vasopressors & inotropic medication Transfusion of blood products, albumin, crystalloids Invasive pressure monitoring
Respiratory haemostasis	Mechanical ventilation Supplemental oxygen Artificial airway (endotracheal or tracheostomy tube, oropharyngeal airway) Extra Corporeal Membrane Oxygenation
Renal haemostasis	Haemodialysis Peritoneal dialysis Haemofiltration
Neurologic haemostasis	Cerebrospinal fluid drainage Intracranial pressure monitoring Hyperventilation techniques Steroids/mannitol
Treatment of infection, inflammation or neoplasm	Antibiotics, antifungal, antiviral medication Immunosuppressive/ anti-inflammatory medication Cytotoxic medication Radiation therapy
Nutritional haemostasis (artificial hydration and nutrition)	Total parenteral nutrition Enteral (tube/ gastrostomy) feeding Intravenous fluids
“Routine” measures	Frequent phlebotomy for laboratory tests Frequent vital sign measurements Radiologic examinations Aggressive chest physiotherapy and endotracheal suctioning Placement of intravenous and intra-arterial lines, urinary catheters

4. **Artificial nutrition and hydration:** refers specifically to those techniques for providing nutrition or hydration that bypass the normal swallowing process. It is now accepted that providing nutrition and hydration via tube or intravenously constitutes a medical treatment (AAP guidelines, 1994). Evidence suggests that neither nutrition nor hydration in terminally ill patients increases the comfort or quality of life, and may in fact exacerbate discomfort and suffering (American Dietetic Association, 2002). In these situations the goal is to provide comfort, not adequate nutrition. Good practice should include moistening their mouths as necessary to keep them comfortable. There are three major categories in which it is ethically permissible to forgo artificial nutrition in children: neurological devastation, irreversible total intestinal failure and imminent death from any cause (Nelson, 1995). However, it is recognized that many health professionals and families are emotionally uncomfortable with forgoing artificial nutrition and hydration, on the premise that feeding children is the most basic aspect of care. Discussions with the family about the consequences of forgoing artificial nutrition and their beliefs and preferences are necessary. Informed and shared decision making is the best ethical practice, but respect for the opinion of the family is paramount.
5. **Brain death:** Denotes the irreversible cessation of all functions of the brain, including the brain stem. There should be no confusion over the concept and definition of brain death - a child who is brain dead is dead. It is a legally defined state that does not require agreement or consent from the family (Report of Special Task Force (1987). Discontinuing technologic support for a brain dead patient is not an issue, and is distinctly different from the issues of withdrawing or withholding LMST in a patient who has an extremely poor prognosis for survival but does not meet the criteria for brain death.
6. **Palliative care:** sometimes referred to as "end of life care". When cure or recovery is no longer possible, the focus must shift to ensuring that the patient has a "good death", with relief from pain and suffering. Both humanistic and technical skills are required to ensure that the needs of the child and family are met. However, patients and their families do not suddenly switch from the hope of survival to the acceptance of death and pursuit of comfort. This process occurs gradually over varying periods of time, ranging from hours to weeks, depending on the clinical situation. Similarly, forgoing LSMTs rarely happens all at once and is likewise a gradual process that parallels the shift in goals. It should be emphasized that palliative care and LSMT are not mutually exclusive options but rather coexistent.

7. **Futility:** comes from the Latin word *futilis* meaning leaky. In Greek mythology, Aegyptus and Danaus were brothers. Aegyptus decided that his fifty sons would marry Danaus' fifty daughters. Danaus, king of Argos, did not like the idea, so he told his daughters to kill their husbands on their wedding nights and supplied them with ruby tipped poisoned pins to stick into their hearts. All of the Danaides did so except one, who fell in love with her husband. The daughters who obeyed their father were condemned by Hades to draw water in leaky sieves. Needless to say, their labours went for naught. The story carries in all its fullness the meaning of the term, useless or incapable of being achieved, no matter how often repeated.

8. **'Forego'** refers to both stopping a treatment already begun as well as not starting a treatment. There is no important ethical or legal distinction between not instituting a treatment and discontinuing treatment already initiated although many health care professionals feel reluctant to discontinue life-sustaining treatments (AAP guidelines, 1994).

UNITED NATIONS CONVENTION ON THE RIGHTS OF THE CHILD

The United Nations Convention on the Rights of the Child and the Malaysian Child Act 2001 defines a child as a person under the age of 18 years.

Article 3 of the UN Convention on the Rights of the Child states that “all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.” The child shall be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child and his/her views be given due weight in accordance with the age and maturity of the child. Malaysia signed this convention on 28 December 1994 and ratified it with 12 reservations in February 1995.

LEVELS OF EVIDENCE SCALE

Level	Strength of Evidence	Study Design
1	Good	Meta-analysis of RCT, Systematic review
2	Good	Large sample RCT
3	Good to Fair	Small sample RCT
4	Good to Fair	Non-randomised controlled prospective trial
5	Fair	Non-randomised controlled prospective trial with historical control
6	Fair	Cohort studies
7	Poor	Case-control studies
8	Poor	Non-controlled clinical series, descriptive studies multi-centre
9	Poor	Expert committees, consensus, case reports anecdotes

Adapted from Catalonian Agency for Health Technology Assessment & Research, (CAHTAR) Spain