

**Withholding or Withdrawing
Life Sustaining Treatment
in Children:
A Framework for Practice**

Second Edition

May 2004



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Royal College of Paediatrics and Child Health

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Foreword to the Second Edition

In 1997 the late Professor David Baum wrote the foreword to the first edition of *Withholding and Withdrawing Life Saving Treatment in Children*. The reasons for its production are clearly stated in his excellent foreword which is reproduced below. The need for such a ‘framework for practice’ is just as evident today. Much has happened during the last seven years and the climate of medical practice has changed. Feedback that we have received from the first edition is that it has been a very helpful framework for thinking through difficult ethical issues. The publication has stood the test of time well. However, a second edition is now needed to take into account changes in legislation and legal cases, along with developments in medical treatment. There are in addition new sections on Palliative Care and Clinical Ethics Committees.

Withdrawing or withholding treatment is one of the most difficult areas of clinical practice and we hope that the second edition of an already proven valuable document will provide the framework to help all healthcare professionals, children and families to come to the right conclusions.

We commend this new edition to you and as always would welcome feedback.

Professor Alan Craft, President, RCPCH, April 2004

Foreword to the First Edition

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

This important document provides a framework on which to construct a reasoned and compassionate approach towards withholding or withdrawing treatment from our patient. It represents the product of some two years’ research and scholarship, framed within the existing law and upholding the rights of the child. It offers a perspective on this, our most difficult area of paediatric practice. I welcome it and commend it to you, in the best interest of the child.

Professor David Baum, President, RCPCH, September 1997

Preface

The first edition of this publication arose in response to the 1994 House of Lords Select Committee Report on Medical Ethics, which noted that the practice of withdrawal of medical treatment was used in intensive care and might be common. In preparing the first report there were a series of workshops, public meetings and many Committee Meetings of the Ethics Advisory Committee to identify and discuss the issues raised in withdrawing treatment. The views of a wide variety of paediatricians and paediatric nurses was sought and included. Discussion was also held with representatives of different religious beliefs (Muslim, Buddhist, Humanist, Jewish and Christian – Protestant, Catholic and Jehovah’s Witness) and advice taken. There was input from parents and patient groups representing those having had stillbirths or neonatal deaths and from individuals with disabilities themselves.

Discussion on the subject of withholding or withdrawal of life sustaining treatment in children is contentious, difficult and at times emotive. The achievement of total consensus in such a subject is probably impossible, particularly with so many consulted, but the common ground we found was considerable and the documents we have produced reflects this, while also taking account of sincerely held individual opinions. The documents have had much redrafting each gradually changing the wording and emphasis in accord with the wishes of those attending the meetings or advising us. We hope that this wide consultation has increased the consensus and is not reflected in fragmentation.

In preparing the second edition we found that the Framework has been widely used and has been of great assistance in informing constructive debate and resolution in this difficult area. Much of the first edition has stood the test of time, but we recognise there have been a number of changes in paediatric practice since 1997 as well as new legislation in this area. We were very grateful for the contributions of Hazel McHaffie on the parent’s perspective of withdrawing treatment, Professor Jonathan Montgomery for assessing the impact of the Human Rights Act and other new legislation and for Professor Richard Cooke on auditing the use of the framework in a busy neonatal practice.

The title of the second edition has changed from “life saving treatment” to “life sustaining treatment” to reflect the fact that the treatment that is often given is not curative but supportive.

However the basic principles outlined in the first edition remain intact. **The framework is not a prescriptive formula to be applied in a rigid way in all cases but an attempt to guide management in individual cases with the fundamental aim to consider and serve the best interests of the child.**

Ethics Advisory Committee Membership

Professor Michael A Patton	<i>Professor of Medical Genetics, St George's Hospital Medical School, London</i>
Mr Phillip Bates	<i>Lecturer, Faculty of Law, Kings College, London</i>
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Mrs Hillary Whitby	<i>Lay representative</i>
Mrs Maureen Robinson	<i>Committee Administrator</i>

Acknowledgements

Previous members of the working party Professor Neil McIntosh, Dr Priscilla Alderson, Miss Gosia Brykczynska, Professor The Rev. Gordon Dunstan CBE, Professor David Harvey, Professor David Hatch, Mr Ewen MacKinnon, Dr Richard H Nicholson, Professor Marcus Pembrey, Mrs Pauline Shelley. A special thank you to Professor Neil McIntosh for his continued interest and support.

Summary

The RCPCH acknowledges that all members of the child health team, in partnership with parents, have a duty to act in the best interests of the child. This includes sustaining life, and restoring health to an acceptable standard. However there are circumstances in which treatments that merely sustain 'life' neither restore health nor confer other benefit and hence are no longer in the child's best interests.

There are five situations where it may be ethical and legal to consider withholding or withdrawal of life sustaining medical treatment¹:

1. ***The "Brain Dead" Child²***. In the older child³ where criteria of brain-stem death are agreed by two practitioners in the usual way⁴ it may still be technically feasible to provide basal cardio-respiratory support by means of ventilation and intensive care. It is agreed within the profession that treatment in such circumstances is futile and the withdrawal of current medical treatment is appropriate.
2. ***The "Permanent Vegetative" State^{5,6}*** The child who develops a permanent vegetative state following insults, such as trauma or hypoxia, is reliant on others for all care and does not react or relate with the outside world. It may be appropriate to withdraw or withhold life-sustaining treatment.
3. ***The "No Chance" Situation***. The child has such severe disease that life-sustaining treatment simply delays death without significant alleviation of suffering. Treatment to sustain life is inappropriate.

¹ Withdrawal of curative medical treatment should signal the initiation of palliative care if this has not already been introduced. see section 3.2.4.

² Definition – Brain death occurs when a child has sustained either (i) irreversible cessation of circulatory and respiratory functions or (ii) irreversible cessation of all functions of the entire brain including the brain stem. A determination of death must be made in accordance with accepted medical standards.

³ Original definitions of brain death were not applied to neonates as criteria were thought to be affected by brain immaturity.

⁴ Task force for the determination of brain death in children. "Guidelines for the determination of brain death in children." *Annals of Neurology*. (1987)**21**:616-617. *Pediatrics*. (1987)**80**:298-299.

⁵ *The vegetative state – guidance on diagnosis and management*. A Report of a working party of the Royal College of Clinical Medicine (2003)**3**: 249-254. Defines the vegetative state and uses the terms "persistent" to mean a vegetative state that has persisted for four weeks or more and "permanent" when the vegetative state is deemed to be permanent and it is predicted that awareness will never recover.

⁶ "The persistent vegetative state." Conference of Medical Royal Colleges and their Faculties of the United Kingdom. *Journal of the Royal College of Physicians, London*. (1996)**30**: 119-121.

4. ***The “No purpose” Situation.*** Although the patient may be able to survive with treatment, the degree of physical or mental impairment will be so great that it is unreasonable to expect them to bear it.

5. ***The “Unbearable” Situation.*** The child and/or family feel that in the face of progressive and irreversible illness further treatment is more than can be borne. They wish to have a particular treatment withdrawn or to refuse further treatment irrespective of the medical opinion that it may be of some benefit.

In situations that do not fit with these five categories, or where there is uncertainty about the degree of future impairment or disagreement, the child’s life should always be safeguarded in the best way possible by all in the Health Care Team, until these issues are resolved.

Decisions must never be rushed and must always be made by the team with all evidence available. In emergencies it is often doctors in training who are called to resuscitate. Rigid rules, even for conditions which seem hopeless, should be avoided, and life sustaining treatment should be administered and continued until a senior or more experienced doctor arrives.

The decision to withhold or withdraw life sustaining therapy should always be associated with consideration of the child’s overall palliative or terminal care needs. These include symptom alleviation and care, which maintains human dignity and comfort.

1. Introduction

All members of the Child's Health Care Team⁷, together with the parents (see section 2.5), have the common purposes of restoring health and sustaining the life of the child⁸. Advancing technology makes it possible to achieve these objectives in circumstances previously regarded as hopeless. However treatments exist that may promote and sustain life but confer no foreseeable benefit for the child. Such treatments may sometimes cause suffering to the child and the family. The background to all treatments, now and in the future, must be that **they should be in the child's best interests**.

It is clear that many professionals, patients and families need some help in making the difficult decisions on when and how life sustaining treatment is to be withheld or withdrawn. The purpose of this document is to provide practical help, framed within the existing law, and upholding the rights of children. As such this document is not intended to be prescriptive or specific but to enable decision making with the child's best interests at heart in a framework of good medical practice. **It is unrealistic to expect complete consensus therefore the aim is to seek as much common ground as possible, while acknowledging sincerely held differences of opinion.**

To this end the Ethics Advisory Committee of the Royal College of Paediatrics and Child Health (EAC-RCPCH) has defined five categories in which the withholding or withdrawal of life sustaining medical treatment might be appropriate and in which the goals of care are redirected. These are set out in the preceding summary. In no circumstances is it appropriate to withdraw palliative care designed to make the patient comfortable.

⁷ The Health Care Team consists of nursing staff, play specialists, educational specialists, medical staff (inclusive of the General Practitioner), and staff from the professions allied to medicine. The team would in all cases work closely with the parents and the child.

⁸ As endorsed by the Children Act (England and Wales 1989; Scotland 1995) and United Nations Convention on the Rights of the Child 1989

2. Background Considerations

2.1 To withhold or withdraw

Withholding or withdrawing life sustaining treatment does not imply that a child will receive no care. It should rather signal a change in focus towards palliative care making sure that the rest of the child's life is as comfortable as possible.

Ethically the withholding and the withdrawal of life sustaining treatment are equivalent but emotionally they are sometimes poles apart. If the decision from the outset is that any treatment other than palliative care would not be in the child's interests, then the decision requires that no resuscitative action is taken. On the other hand if the decision is taken after treatment intended to continue life has been instituted, the decision will lead to a change in the treatment plan with active withdrawal of life sustaining treatment with emphasis on palliative care. Some paediatricians and parents find the second course psychologically and emotionally the more difficult but on the other hand in this situation it may be easier for the parents to believe that everything possible has been done.

In acute situations it is always necessary to give life-sustaining treatment first and to review this when enough information is available, from more experienced opinion or following the evolution of the clinical state or in the light of investigations. Neonates should almost always be resuscitated in the labour ward, particularly if there has been no prior discussion. Withholding or withdrawal decisions should be made by experienced senior staff.

In critical care areas⁹ there should be frequent review of all decisions including those related to provision of life sustaining treatment. There should be a willingness to change with changing circumstances.

2.2 The extent of withholding and withdrawal of care in paediatric practice

There is substantial evidence that it is common and accepted practice to withdraw life-sustaining care where parents and medical staff believe that the distress incurred by such care outweighs the benefits.

⁹ Critical care areas include A&E, labour ward and intensive care units.

2.2.1 Neonatal practice

Recent statistics show that discussions with parents about limitation and possible withdrawal of treatment may occur in up to 70% of deaths in UK neonatal intensive care units.¹⁰

Examples of clinical situations where treatment may not be started, may be discontinued, or may be limited include:

- Non-resuscitation of a baby at birth with a congenital abnormality that is incompatible with survival, such as the absence of a large part of the brain (anencephaly).
- Non-resuscitation of a baby born with a confirmed gestational age of 23 weeks or less when parents accept the neonatologist's opinion that survival would be so likely to be associated with severe neurological impairment that the many weeks of intensive care cannot be justified.
- Withdrawal of artificial ventilation from a baby who has suffered birth asphyxia and in whom investigation has revealed profound brain damage.

2.2.2 Practice later in childhood

Withdrawal of treatment in paediatric intensive care units accounts for between 43% and 72% of deaths¹¹ in the UK and other countries where it has been studied.

In the management of children with chronic conditions outside intensive care similar decisions are also made but much fewer data are available¹². At least 12 in 10,000 children are living with a life-threatening condition in this country.¹³ Many of these children receive palliative care at home where choices to withhold invasive and intensive interventions are made regularly¹⁴.

¹⁰ McHaffie HS et al. *Crucial Decisions at the beginning of Life*. Radcliffe Medical Press (2001).

¹¹ McCallum DE, Byrne P and Bruera E. "How children die in hospital." *J Pain Symptom Management*. (2000) **20**:417-23.

Keenan SP, Busche KD, Chen LM et al. "Withdrawal and withholding of life support in the intensive care unit: a comparison of teaching and community hospitals." The Southwestern Ontario Critical Care Research Network. *Crit. Care. Medicine* (1998); **26** (2)245-51.

Goh AY and Mok Q. "Identifying futility in a paediatric critical care setting: a prospective." *Arch Dis Child*. (2001) **84**: 265-8.

Cuttini. M et al. "End-of-life decisions in neonatal intensive care: physicians' self reported practices in seven European countries." *Lancet*. (2000)**355**: 2112-2118.

¹² Liben S, Goldman A. "Homecare for children with life threatening illness." *J of Palliative Care* (1998) **14**: 33-38.

¹³ *A Guide to the Development of Children's Palliative Care Services. Report of a Joint Working Party of the Association for Children with Life-threatening or Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health*. September 2003.

¹⁴ Goldman A, Beardsmore A, Hunt J. "Palliative Care for Children with Cancer – home hospital or hospice?" *Arch Dis Child* (1990) **65**:641-643.

Lewis M. "The Lifetimes Service: a model for children with life-threatening illnesses and their families." *Paediatric Nursing*. (1999) **11**:21-23.

Examples in later childhood might include:

- The withholding of antibiotics to treat pneumonia or other life threatening infection in the case of a seriously neurologically impaired child or child suffering from a terminal illness. In contrast, antibiotics might be used for a non-fatal infection which is causing distress, such as a painful middle ear infection (acute otitis media). This latter step would represent an important element of good palliative care.
- The paediatric neurologist might consider the appropriateness of ventilator care in an infant with progressive respiratory failure from anterior horn cell disease.¹⁵ He or she might consider withdrawing all life sustaining care from a severely injured child where brain stem responses are absent on two occasions.
- When there is no expectation of a cure being achievable the paediatric oncologist might withhold antibiotics in a child with multiple secondary deposits of tumour. He might also withdraw chemotherapy in leukaemia if the child had previously suffered frequent relapse and the course of therapy was giving little benefit.

2.3 The Ethical Framework

No single ethical framework is likely to embrace all views on questions of withholding or withdrawing treatment but the EAC-RCPCCH were mindful of a number of ethical theories and principles in shaping their recommendations.

2.3.1 Fundamental Principles

The EAC-RCPCCH believes that three fundamental principles apply:

2.3.1.1 *Duty of Care and the Partnership of Care.* Granted the compelling presumption in favour of life, the Health Care Team has a duty of care with the primary intention of sustaining life and restoring their patients to health. Whether or not the child can be restored to health, there is an absolute duty to comfort and to cherish the child and to prevent pain and suffering.

In fulfilling the obligations imposed by the duty of care, the Health Care Team and parents will enter a partnership of care, whose function is to serve the best interests of the child. This duty of care also involves respecting the ascertainable wishes and views of children in the light of their knowledge, understanding and experience. Children

¹⁵ Hardart MKM, Truog RD. "Spinal muscular atrophy – Type 1." *Arch. Dis. Child.* (2003) **88**:848-850.

should be informed and listened to so that they can participate as fully as possible in decision making.

2.3.1.2 *The Legal Duty* All Health Care professionals are bound to fulfil their duty of care within the framework of the law. The law governing issues of withdrawal or withholding treatment is complex and arguably inconsistent, but it is clear that any practice or treatment given with the primary intention of causing death is unlawful.

The Children Act (England and Wales, 1989; Scotland, 1995) provides an overall statutory framework for the provision of children's welfare and services but makes no specific provision concerning withholding or withdrawing treatment. It does however, provide *inter alia* that:

- The child's welfare is paramount.
- Particular regard is paid to the ascertainable wishes and feelings of the child.
- Children of sufficient maturity and understanding may be allowed to refuse medical or psychiatric examination or other assessment (but only for the purposes of a child assessment order [section 43(8)] or an emergency protection order [section 44(7)].)

However, the Act also introduces the concept of parental responsibility (section 2.5). Those with parental responsibility may make decisions on behalf of children provided that they act in their child's best interests. Parental responsibility can be acquired under the Act by people who are not the child's natural parents. This increases the number of people who could be involved in making decisions about children. Judgements under the common law would appear to allow a child who is able to understand fully the nature and purpose of medical treatment to consent. By inference, it would seem that the child could refuse life saving or life sustaining treatment, but decisions of the Court of Appeal *re R and re W*¹⁶ have established that those with parental responsibility can over-ride a child's refusal even if the child concerned is capable of fully understanding the consequences of the decision. In cases of disagreement, a court can be asked to consider whether continuing treatment would be in the best interests of the child and can override the objections of both parents and competent children.

A number of judgements on withholding or withdrawing life sustaining treatment have established that:

- There is no obligation to give treatment which is futile and burdensome - indeed this could be regarded as an assault on the child.
- Treatment goals may be changed in the case of children who are dying.

¹⁶ Re R (1991) 4 All ER 177, 185 Re W (1992) 4 A11 ER 627, 633

- Feeding and other medical treatment may be withdrawn in patients in whom the vegetative state is thought to be permanent (but in each case, it is suggested that legal advice should be taken).
- Treatment may be withdrawn from patients if continuation is not in their best interests.

Decisions concerning withholding or withdrawing treatment in the best interests of the child would probably need to fulfil the Bolam test.¹⁷ That is, a responsible body of professional opinion would be of the view that it was not in the best interests of the child to continue treatment for reasons that are logical and stand up to analysis.

2.3.1.3 *Respect for Children's Rights* The United Nations Convention on the Rights of the Child (1989), which has been ratified by the British Government, sets out fundamental principles which govern how children should be treated. The following are the most relevant for the purposes of this document:

- Article 3 states that action affecting children should have 'their best interests' as a primary consideration.
- Article 24 confirms the right of the child to the highest obtainable standards of health and to facilities for the treatment of illness and the rehabilitation of health.
- Article 13 confirms the child's right of freedom of expression and to seek, receive and impart information and ideas of all kinds.
- Article 12, affirms that 'a child who is capable of forming his/her view has the right to express those views freely on all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child'.

The Convention also affirms the right of families to be given all necessary support in caring for their child and in the performance of their child rearing responsibilities.

2.3.2 Axioms on which to base practice

From these fundamental principles flow a number of general axioms which may govern practice. These are:

2.3.2.1 There is no significant ethical difference between withdrawing (stopping) and withholding treatments, given the same ethical objective.

2.3.2.2 Optimal ethical decision-making concerning children requires open and timely communication between members of the Health Care Team and the child and family,

¹⁷ Bolam v Friern HMC (1957)2 All ER 118

respecting their values and beliefs and the fundamental principles of ethics and human rights.

2.3.2.3 Parents may ethically and legally decide on behalf of children who are unable, for whatever reason, to express preferences, unless they are clearly acting against the child's best interest or are unable, unwilling or persistently unavailable to make decisions on behalf of their child.

2.3.2.4 The wishes of a child who has obtained sufficient understanding and experience in the evaluation of treatment options should be given substantial consideration in the decision making process.

2.3.2.5 The antecedent wishes and preferences of the child, if known, should also carry considerable weight given that conditions at the time for action match those envisaged in advance.

2.3.2.6 In general, resolution of disagreement should be by discussion, consultation and consensus.

2.3.2.7 The duty of care is not an absolute duty to preserve life by all means. There is no obligation to provide life sustaining treatment if:

- its use is inconsistent with the aims and objectives of an appropriate treatment plan
- the benefits of that treatment no longer outweigh the burden to the patient.

2.3.2.8 It is ethical to withdraw life sustaining treatment if refused by a competent child; or from children who are unable to express wishes and preference when the Health Care Team and parent/carers agree that such treatment is not in the child's best interests.

2.3.2.9 A redirection of management from life sustaining treatment to palliation represents a change in beneficial aims and objectives and does not constitute a withdrawal of care.

2.3.2.10 The range of life sustaining treatments is wide and will vary with the individual circumstances of the patient. It is never permissible to withdraw procedures designed to alleviate pain or promote comfort.

2.3.2.11 There is a distinction to be drawn between treatment of the dying patient and euthanasia. When a dying patient is receiving palliative care, the underlying cause of death is the disease process. In euthanasia, the intended action is to cause death.

2.3.2.12 It follows that use of medication and other treatments which may incidentally hasten death may be justified if their primary aim is to relieve suffering. The EAC-RCPCH does not support the concept of euthanasia.

2.3.2.13 Legal intervention should be considered when disputes between the Health Care Team, the child, parents and carers cannot be resolved by attempts to achieve consensus.

2.4 The Legal Framework

The courts have accepted that it is lawful to withdraw life-prolonging treatment when the quality of life the child would have to endure if given the treatment would be so afflicted as to be intolerable to the child¹⁸. Although there has not yet been a case involving a child, the implementation of the Human Rights Act 1998 has not altered the courts' view that withdrawing such treatment in appropriate cases is consistent with patients' human rights.

Although it is necessary and fundamental to practice within the framework of the law, the EAC-RCPCH believe it is important to define best practice in relation to the interests of the family and the child rather than presenting the minimum legal requirement. We must look at what is legally permitted and required, but also at what is ethically appropriate, which may exceed the minimum standards set by law.

If a doctor wishes to continue treatment of a very ill child, but there is room for reasonable doubt about the benefit, the doctor may be in a difficult position if he continues when the parents have withheld or withdrawn consent. A court might say that the doctor did not act in the child's best interests. In cases of dispute it is good practice to consult the court¹⁹. In the meantime, the treatment should be given in the expectation that the court will support the action.

¹⁸ *Re J* (1991) Fam 33 and *Re c* (1998) 1FLR 384
NHS Trust v M: NHS Trust v H (2001) 2FLR 367

¹⁹ Matters regarding health would normally be considered in a High Court. Court "orders" can only prohibit an intervention or authorise one if deemed medically expedient and in the patient's interests. They cannot oblige doctors to any specific medical intervention. In Scotland a doctor must take responsibility for his treatment decisions and the courts have little or no authority to give sanction to such decisions in advance.

2.4.1. The legal context behind a child's consent

In England and Wales in 1985, the Gillick ruling established that children who are capable of fully understanding the implications of their decisions can give valid consent and that parents have rights only in so far as these enable them to exercise responsibilities to benefit their children. More recent court rulings in 1991 and 1992 have retreated from the original Gillick level of respect for the competent child's views; they have reaffirmed parents' rights of consent as a necessary legal protection when doctors care for minors. The courts have previously regarded the appropriateness of enforcing treatment on resisting children as an ethical not a legal matter²⁰

However, case law in relation to adults suggests that imposing treatment in such circumstances may constitute 'inhuman and degrading treatment' that breaches human rights unless it is 'medically necessary' to do so. It is accepted that 'medical necessity' can be present even when a decision is controversial, but the concept has not yet been further defined by the courts.

The 1969 Family Law Reform Act respects consenting decisions of young people aged over 16 years as if they are adults, but not necessarily dissenting decisions. A dissenting child at any age is likely to have his or her views overridden. This is despite the 1989 Children's Act and the UN Convention, which both take a broad view of involving even 'non-competent' children (who may nevertheless hold important and informed views) into decision making. Such views can help adults to make more informed decisions.

2.4.2. The Convention of the Rights of the Child

The United Nations Convention on the Rights of the Child (1989) cannot be directly applied in UK courts, but ratification means that Governments undertake to honour the Convention and to report regularly to the United Nations on their progress in implementing children's rights. The Convention states that actions affecting children must have the 'best interests of the child' as a primary consideration (Article 3). It also enshrines 'the right of the child to enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and the rehabilitation of health' (Article 24) subject to the resources available (Article 4). The Convention also respects the child's right 'to freedom of expression (including) freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers'

²⁰ Re R (1991) 4 All ER 177, 185 Re W (1992) 4 All ER 627, 633.
R (On the Application of Wilkinson) v Broadmoor SHA (2002) 1 WLR 419
R (On the Application of N) v Dr M (2003) 1 FCR 124

and in ‘media of the child’s choice’ whether language, drawings and visual aids, or through other kinds of communications (Article 13).

Like English law, the Convention respects the rights of all children to form and express their view and states that “the child who is capable of forming his or her own views has the right to express those views freely on all matters affecting the child, the views of the child being given due weight in accordance with the age and maturing of the child”.

Thus the Convention addresses the child’s right to share in decision-making, but does not address questions of the child being the main or sole decider about proposed health care. The Convention does not affect any state laws which go further than the Convention (Article 41). English law has gone further, in recognising the rights of competent children to make decisions in certain circumstances²¹.

2.4.3. Euthanasia²²

Withdrawal of life sustaining treatment in appropriate circumstances is not seen by the courts as active killing, nor as a breach of the right of life under article 2 of the European Convention on Human Rights²³.

Where withdrawal of ventilatory support does not lead to death, it must be made clear that euthanasia is not appropriate and that palliative care should be offered. The lives of unexpected survivors, even when badly disabled, should be respected and they should be cared for appropriately.

Some clinicians consider euthanasia acceptable practice: others believe that it is never acceptable. The Committee acknowledges the debate about euthanasia and changing clinical practice in some countries will continue to receive public attention²⁴. The EAC-RCPC does not support euthanasia.

Giving a medicine with the primary intent to hasten death is unlawful. Giving a medicine to relieve suffering which may, as a side effect, hasten death is lawful and can be appropriate.

²¹ Gillick v Wisbech & W Norfolk AHA (1985) 3 All ER 402; Children Act 1989. part V, 43, 44.

²² Definition – Causing death by intended lethal action, but for the relief of suffering

²³ Airedale NHS Trust v Bland (1993) 1 All ER 821; NHS Trust v M; NHS Trust v H (2001) 2 FLR 367

²⁴ Cuttini, M. et al. “Should euthanasia be legal? An international survey of neonatal intensive care units staff.” *Arch. Dis. Child* (2004) **89**:F19-F24.

Lagercrantz, H. “Commentary on paper Cuttini et al.” *Arch. Dis. Child*. (2004) **89**:F2

Cooke, RW “Commentary on paper Cuttini et al.” *Arch. Dis. Child* (2004) **89**:F3.

It is recognised in English and Scottish law that increasing doses of analgesia necessary for control of pain or distress may shorten life. The giving of opioids is for the benefit of the patient during life not in order to cause or hasten death.

2.5. Parental responsibilities²⁵

Under the UN Convention on the Rights of the Child the State has a duty to support parents in this responsibility. It is the duty of the parents to act for the child and in the best interests of the child. The parents will always be participants in the care and decision making. The child will be involved to a degree appropriate for their experience and condition.

Although parents act for the child, they often feel unsure of where they can go for extra advice outside the immediate Health Care Team and their decisions may be altered by the way in which the information is presented to them. Sometimes there may be a need for an advocate not connected with the medical team. Such a person may not only be able to interpret medical information to parents and child in understandable language, but - more importantly - assist the parents or child in conveying their views accurately to the professionals.

If the local authority achieves a care order it gains parental responsibility and the power to restrict the natural parents' authority or that of any other person who would normally carry such authority. Parents can appeal to the High Court and to the Court of Appeal.

2.6. Involving Children

2.6.1. Competence

Children's competence is related to their experience as well as their developmental stage. Very young children who have had two courses of chemotherapy or two organ transplants will often have more informed views about proposals for a third course of treatment than adult patients who are considering such treatment for the first time. Other young children have no experience of decision making and their framework of values remains unformed.

The EAC-RCPCH believes that there should be a presumption of competence, unless a

²⁵ A child's mother automatically has parental responsibility. A father does not have parental responsibility unless he has married the mother, or made a parental responsibility agreement with her, or obtained a court order granting him parental responsibility, or fathers whose name appears on the birth certificate for children born after 12 December 2003. However, it would be good practice for both parents to be fully involved in decision making as far as possible, whether or not the father has parental responsibility. Other individuals can obtain parental responsibility by court order, or by being appointed as a guardian on the death of a parent.

child is obviously incompetent e.g. extreme immaturity. It should be a duty of the professionals to assess the individual child's competency for decision making. Good practice goes beyond observing minimum legal standards (see 2.4.1) and takes account of higher ethical standards of respect for young children's views, as well as concern for their welfare. Open and timely communication between the young patient, family and members of the Health Care Team is central to informed and ethical decision-making. The EAC-RCPCCH sees differences between:

1. informing children,
2. listening to them,
3. taking account of their views so that these can influence decisions, and
4. respecting the competent child as the main decider about proposed health care interventions.

These four levels involve different degrees of competence. The child's rights to be informed and to express views (levels 1 and 2) are conditioned only by the child being able to understand information and to form and express personal views.

2.6.2. Good Practice in Involving Children

The account taken of children's views (see above) varies according to how informed and wise each view is thought to be, and how much the adults concerned respect children's wishes and feelings. Respect for a child's view, including their wish to refuse further interventions, has been quite widely advocated²⁶. Children are increasingly involved in social and nursing decisions about how their treatment is administered.

The real difficulties arise with the most troubling questions: What is the best course of treatment? When does life become not worth living? When is hope of benefit too slight to justify treatment? Such questions can increase doubts about how far it is wise or kind to inform and involve children. When does the child's wish become decisive? How far should parents' refusal to allow the child to be informed or involved be respected? There may be conflicts between children's rights based on competence and parental and medical views. How can children's competence, with their ability to cope with distressing news and to make decisions, be assessed taking account of their best interests? Varied ways of communicating with children and of respecting their physical and mental feelings, beyond

²⁶ For example: Fradd E. "Tug of love." *Nursing Times* (1988) **88**:32-5. Warner J. "Commentary. Early experiences of heart lung transplantation in cystic fibrosis." *Arch Dis Child* (1989) **64**:9-13. Goodwin M, Alderson P. "Contradictions within concepts of children's rights." In *J of Children's Rights* (1989) **1**:303-13. British Medical Association *Consent, Rights and Choices in Health Care for Children and Young People* London: BMJ Books (2001).

cognitive and strictly verbal approaches, are being used. They need to be more widely reported and explained.

In many cases children have no views about proposed care (such as when they are babies, or when illness, injury or disability limit their understanding). In other cases, children prefer others to decide for them; although this apparent preference should be checked and not assumed. Some children want to influence decisions or to be the main decider. Experienced young patients with severe illness or disability may decide that life is not worth living, e.g. those with anorexia or severe mental illness may ask for less enforced treatments. In the latter group, assessments of competence are particularly complicated and it is often assumed that parents or courts know best.

2.7. Impairment and Disability ²⁷

One of the most challenging and difficult areas involves the question of withholding or withdrawing life sustaining treatment for children with severe impairment. (section 3.1.3)

In 1991 the Court of Appeal accepted that it is lawful to withdraw life-prolonging treatment when the quality of life the child would have to endure, if given the treatment, would be so afflicted as to be intolerable to the child²⁸. 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 has been born disabled. The EAC-RCPCH believes that this means when there is little or no prospect of meaningful interaction with others or the environment. In this situation no reasonable person would want to lead such a life, nor impose on a doctor a duty actively to strive to bring it about.

2.7.1. Living with disability

Many people with severe impairment describe a life of high quality and say they are happy to be living it. Impairment is not incompatible with a life of quality. Children and adults may not view their residual disability as negatively as some able-bodied people do, provided adequate support is available. It is important that society does not devalue disabled people or those

²⁷ Definitions – An impairment describes a pathological process such as spina bifida, a disability is the consequence of an impairment and a handicap the social consequence of the impairment or disability. Handicap is a disability of body or mind which interferes with the ability to lead a normal life or to benefit from a normal education. This may constitute a breach of the Disability Discrimination Act 1995 and also the Human Rights Act 1998. A recent example of this is the case of *Glass v The United Kingdom* in the European Court of Human Rights, 2004.

²⁸ *Re J* (1991) *Farm* 33

living with severe impairments. **The EAC-RCPCH strongly believes that the provision of care to those with disability should not be reduced and there must always be a commitment to the provision of high quality care for those with disability.** Sadly there are indications such children have been discriminated against when they compete for acute surgery²⁹.

There is a degree of impairment which includes a loss of awareness and an inability to interact. Perhaps this is intolerable disability. Spastic quadriplegia with very severe cognitive and sensory deficits might be one such condition. The burden is not only for the child but also the parents or their surrogates, and society must also determine how best to share it.

2.7.2. Disability

This is a matter of individual perception. What is tolerable for one person might well be intolerable for another. It is important in counselling to avoid over pessimistic views about life with disability. It is also important to recognise that while some people with disabilities are able to live fulfilled lives others with the same level of disability feel that life is not worth living. It is particularly difficult to assess the acceptability of a disability in the child.

“Very serious handicap” is a term that parents may use when facing a particularly bleak outcome.

2.7.3. An intolerable disability

A severe/intolerable disability is indefinable; there are ways of making it more tolerable, and an individual sufferer, even with extreme disability, may still attach some value to existence. Judgements on disability are bound up in people’s fears and attitudes and can be altered by a change in the environment. Note:

- Intolerable may mean “that which cannot be borne” or “that which people should not be asked to bear”.
- An individual may believe that he/she is an intolerable burden
- An impossibly poor existence may not be recognised by the individual, depending on that person’s cognition.

²⁹ Smith GF et al. “The rights of infants with Down’s syndrome.” *JAMA* (1984) **251**:229.

Bull *et. al.* Should management of complete atrioventricular canal defects be influenced by co-existent Down’s syndrome. *Lancet.* (1985)**ii**: 1147-1149.

A heart for Jo. *The Guardian Weekend.* 10.8.96.

Controversy over disabled girl’s death in casualty unit. *The Sunday Telegraph.* 29.12.96.

R v Central Birmingham HA ex parte Walker (1987)3 BMLR 32.

It is possible to envisage a level of disability that doctors believe to be intolerable, i.e. no reasonable person would want to live with it, and yet an individual sufferer may attach value to their existence.

3. The Process of Decision Making

3.1 Consideration of withdrawal

In general, the outcome for a clinical problem at the time of presentation is uncertain. The team must wait until enough **information** (not feelings) about the child's clinical condition and other relevant matters to enable a clear decision on whether or not further treatment is appropriate. **All remediable causes for the child's condition must be excluded.** e.g. drugs, metabolic encephalopathy.

The EAC-RCPCH believes however that it is sufficient to have a reasonable belief that a particular outcome is likely and that absolute certainty may be neither possible nor always necessary.

3.1.1 Decision Making

In medicine there are two extremes: where death is certain and where cure is certain. Between these extremes exists uncertainty, and whether or not intervention is worthwhile is a value judgement based on prediction of outcome. Deciding what outcome is intolerable or treatment is unbearable is an intrinsic part of the decision making.

All members of the Health Care Team need to feel part of the decision making process in that their views should be listened to and accorded due weight. Most recognise that the latter will depend on their knowledge, understanding and experience. This applies to both clinical and moral matters. However greater openness between disciplines and grades will facilitate greater understanding of individual roles and responsibilities and enhance the sense of corporate moral responsibility.

Decisions should be made with the parents on the basis of knowledge and trust. Parents and children may have a greater perception of their roles and responsibilities as agents in decision making than professionals acknowledge. In order to maximise active participation of parents and children in the decision-making process, clinical teams need to ascertain the tolerance of parents and children for assuming responsibility and work within that. This should enhance their ability to live with the decision they have made.

Ultimately, the clinical team carries the corporate moral responsibility for decision making, which is an expression of their moral and legal duties as health care professionals. Teams can develop this moral responsibility by reasoning together.

3.1.2. Second opinion

There may however be circumstances when an independent consultation with another clinician or ethics committee may be helpful.

Paediatricians may seek further opinions to enable parents and children to come to terms with prognosis and to provide reassurance for themselves. In practice a decision to withdraw treatment is usually a matter of consensus rather than an individual decision. However, many major medical decisions require a second opinion for legal reasons as well as clinical assurance, e.g. termination of pregnancy, brain stem death. Obtaining a second opinion as to the advisability of withdrawing life sustaining treatment is not a legal requirement but there may be circumstances in which it may highlight the appropriateness of the process of decision making. The circumstances where a second opinion **should** be sought are discussed in section 3.4.

3.1.3. Circumstances of withholding or withdrawal of treatment

The Brain Dead Child³⁰. When brain stem death is confirmed, the patient is by definition dead. Within the patient organs may function due to extraordinary medical assistance: such assistance can appropriately be withdrawn. Brain death must be diagnosed in the usual way by two medical practitioners.

The “Permanent Vegetative State” (PVS)³¹. The vegetative state may follow insults such as trauma or hypoxia. It may persist i.e. be present for four weeks or more or become permanent in that it is predicted that recovery of awareness will never occur. The child in such a state shows no awareness, does not react or relate with the outside world and is reliant on others for all care. Diagnosis in children as in adults depends on the fulfilment of clinical criteria and requires appropriate assessment. In such circumstances treatment, inclusive of tube feeding, may³² be withdrawn whilst making the patient comfortable by nursing care.

³⁰ Definition – Brain death occurs when a child has sustained either (i) irreversible cessation of circulatory and respiratory functions or (ii) irreversible cessation of all functions of the entire brain including the brain stem. A determination of death must be made in accordance with accepted medical standards.

³¹ Definition – A state of unawareness of self and environment in which the patient breathes spontaneously, has a stable circulation and shows cycles of eye closure and eye opening which simulates sleep and waking, for a period of 12 months following a head injury or 6 months following other causes of brain damage.

³² The legal judgement on Bland (Airedale NHS Trust v Bland (1993) 1 A11 ER 821) suggests that in this situation tube feeding is itself an assault and so it should be withdrawn. In paediatric practice this is less clear – see 3.1.4.

The “No Chance” Situation. Treatment delays death but neither improves life’s quality nor potential. Needlessly prolonging treatment in these circumstances is futile and burdensome and not in the best interests of the patient; hence there is no legal obligation for a doctor to provide it. Indeed, if this is done knowingly (futile treatment) it may constitute an assault or “inhuman and degrading treatment” under Article 3 of the European Convention on Human Rights. Consider for example a child with progressive metastatic malignant disease whose life would not benefit from chemotherapy or other forms of treatment aimed at cure.

The “No Purpose” Situation. In these circumstances the child may be able to survive with treatment, but there are reasons to believe that giving treatment may not be in the child’s best interest. For example, the child may develop or already have such a degree of irreversible impairment that it would be unreasonable to expect them to bear it. Continuing treatment might leave the child in a worse condition than already exists with the likelihood of further deterioration leading to an “impossibly poor life”. The child may not be capable now or in the future of taking part in decision making or other self directed activity.

In all the above circumstances it is appropriate to consider withholding or withdrawing treatment. If it is likely that future life will be “impossibly poor” then treatment might reasonably be withheld. If such a life already exists and there is likelihood of it continuing without foreseeable improvement, treatment might reasonably be withdrawn.

“The Unbearable Situation”. This situation occurs when the child and/or family feel that further treatment is more than can borne they may wish to have treatment withdrawn or to refuse further treatment irrespective of the medical opinion that it may be of some benefit.

3.2. Clinical responsibilities of the Health Care Team

Treatment generally requires co-operation. The Health Care Team must always act in the child’s best interests. The Health Care Team must not inflict treatment on children just because a treatment becomes available, but always introduce treatments for the benefit of the child, withdrawing them when they are no longer of benefit.

The clinical team will almost always have to start from a premise of uncertainty. It is crucial to wait until enough information is available to decide on the individual outcome. It is recognised that such delay may become a source of tension within the Team. This information must include a clear diagnosis where possible and an awareness of the likely prognosis, given an appraisal of the possible therapeutic options. Decisions to stop or withhold certain treatments will almost always be based on probabilities rather than certainties. Some children whose medical treatment is withdrawn go on to survive³³ and it is not a wrong decision if this is the outcome. Treatment

is withdrawn because it is futile but not with the intention that to do so will bring about death. Continuing support, respect and palliative care is required for the unexpected survivor. In the situation where treatment is being withheld the Team need to be flexible in the face of changing circumstances.

3.2.1. Range of treatments

There are many different types and intensities of therapy that it may be appropriate to consider withdrawing or withholding, depending on the severity of the illness or the situation. These may include experimental therapies which are currently not validated by research evidence, cardiopulmonary resuscitation, mechanical ventilation, intravenous inotropic agents, antibiotics, artificial nutrition and intravenous hydration.

Feeding is a particularly emotive area for parents and staff, and opinions vary regarding withholding and withdrawal of feeding. The role of assisted feeding for an infant or child (by nasogastric tube or gastrostomy) should be considered very carefully and discussed fully with the family. It may be entirely appropriate, for example, in a child with a swallowing disorder due to a slowly progressive neurodegenerative disease, but would rarely be introduced for a child with rapidly progressive, disseminated malignant disease. In other circumstances, its withdrawal can be accepted if it is well managed.³⁴

3.2.2. Muscle relaxants

The use of paralysing agents prior to withdrawal of ventilatory support can be viewed in a similar way. In some situations, such as severe lung disease, synchrony with a mechanical ventilator which is a necessary part of effective treatment, can only be achieved by administering a muscle paralysing agent in addition to sedatives and analgesics.

If it subsequently becomes appropriate to consider withdrawal of ventilation, it is important

³³ Vernon DD et al. Modes of death in the paediatric intensive care unit: withdrawal and limitation of support care. *Critical Care Medicine* (1993) **21**:1798-1802. Mink RB and Pollock MM. Resuscitation and withdrawal of therapy in paediatric intensive care. *Pediatrics* (1992) **89**:961-963. Lantos JD et al. Do-not-resuscitate orders in a children's hospital. *Critical Care Medicine* (1993) **21**:52-55. Ryan CA et al. No resuscitation and withdrawal of therapy in a neonatal and paediatric intensive care unit in Canada. *J Pediatr* (1993) **123**:534-538.

Martinot A et al. All modes of death in a French paediatric intensive care unit. *Proceedings of the European Society for Pediatric Intensive Care*. (1994).

Levetown M et al. Limitations and withdrawals of medical interventions in pediatric critical care. *JAMA* (1994)**272**:1271-5.

Balfour-Lynn IM and Tasker RC. Futility and death in paediatric medical intensive care. *J Med Ethics* (1996)**22**:279-281.

³⁴ Airedale NHS Trust v Bland (1993) 1 All ER 821

to remember that there is a difference between managing the process and ensuring death. It may not be in the child's best interests to withdraw the paralysing drugs before discontinuing ventilation, as this action would subject the child to a period of sub-optimal ventilation leading up to withdrawal of ventilatory treatment. Thus, when a decision is made to withdraw mechanical ventilation, a paralysing agent necessarily prescribed for prior treatment may be administered up to (but not beyond) the point that respiratory support is withdrawn. It would however be unlawful to prescribe a paralysing agent prior to withdrawal of treatment simply to avoid terminal gasping which sometimes occurs as ventilation is withdrawn, a situation which should be managed with more appropriate and specific treatment to relieve distress.

In the case of a child with severe brain injury, it is unlikely that a paralysing agent would be required to facilitate curative treatment. As no paralysing agent was required at that stage, such a drug should not be introduced for withdrawal of treatment.

In a child with severe cardiopulmonary failure where paralysing agents have been required to ensure effective ventilation during treatment, death will be inevitable with or without paralysis. In these circumstances, there is no need to stop the paralysing agent prior to withdrawal of treatment.

3.2.3. Palliative Care

The clinical team has a duty always to offer palliative care to children with life-threatening and life-limiting illnesses. It may begin whenever it becomes apparent that the illness may result in premature death. It can be provided alongside treatments aimed to cure or significantly prolong life and should continue as the main focus of care when these treatments are withdrawn or withheld.³⁵ Palliative care should respect the child's dignity and consider their physical needs including the relief of pain and other symptoms, and also address the emotional, social and spiritual needs of both the child and their family. All these aspects of palliative care can be provided wherever a child and family are cared for - whether in hospital, at home or in a children's hospice. Careful planning and communication is needed to ensure continuity of care for the child, particularly when they are moving between hospital and home. A key worker (often the paediatric community nurse) is essential to co-ordinate this, especially where it is anticipated that palliative care may be needed for an extended

³⁵ *Palliative Care for Young People. Report of the Joint Working Party of ACT (The Association for Children with Life-Threatening or Terminal Conditions and their Families), the National Council for Hospice and Specialist Palliative Care Services and the Scottish Partnership Agency for Palliative and Cancer Care. 2001.*

period of time and involve a number of health care professionals. If the illness is prolonged respite care should be available.

3.3 Communication

3.3.1 Within the Health Care Team

When the issue to withhold or withdraw treatment is raised, all members of the clinical team should have an opportunity to voice their feelings and opinions. The weight given to each individual's views should take their experience into account. Some may feel afraid to voice their opinion, so sympathetic encouragement is important. Some units require the whole team to express an opinion and also require unanimity; in others the issue is discussed openly but not everyone may be expected to contribute. It is perhaps unrealistic and may not be in the child's best interests to expect unanimity in support of decisions to withdraw or withhold treatment in all cases. The consultant in charge of the case should lead the decision making process and always bears the final responsibility for the chosen course of action. Team discussions about the patient are a necessary learning experience for the whole team. Senior members should promote this by interpreting information that is shared from their previous experience, but also by considering any new interpretations fairly.

Decisions to withdraw or withhold life-sustaining treatment should be clearly understood and documented by the clinical team.

3.3.2 With the family

When withdrawal is an option that has been raised by the clinical team, the consultant and a senior colleague (nurse or social worker) should, at an early stage and either together or separately, discuss the fact that the issue is to be considered with parents.³⁶ The child, as far as he or she is able, their wider family (eg siblings) and any other individual (religious or social) whom the parents or child nominate should also be involved. For full involvement, the parents (and child if appropriate), must have adequate information and adequate time to understand and assess it, with time also to obtain alternate advice if they so wish. Siblings can have important insights into the feelings of their sick brother or sister. The final decision is made with the consent of the parents though the clinical team must take the main responsibility for the decision. (see 3.1.1.) This can help to alleviate the burden of guilt that some parents feel.

³⁶ Greig-Midlane. H. "The parents perspective of withdrawing treatment" *BMJ* (2001)323:390.

A full record of communication with the family should be written in the clinical record on all occasions. 'Do not attempt resuscitation' orders and decisions to withhold or withdraw life sustaining treatment must be clearly recorded in the child's clinical notes together with a written account of the process and factors leading to this decision.

After the death of the child, the consultant in charge and the nurse most involved should offer to see the parents, to discuss the death and the result of the post mortem examination³⁷ if it is available. A copy of such a report should be given to the parents on request. The parents may wish to meet with other members of the clinical team and such a meeting should be arranged by the consultant or the nursing staff. Valuable continuing support may be given by an involved social worker.

3.3.3 Communication with Primary Health Care and Community Services

When a decision is being made with a family about withdrawing or withholding life sustaining treatment, it will usually be appropriate to include the primary health care team and local paediatric professionals in the discussion, especially if they have known the child and family well. If they are not part of the ongoing discussion it is essential to keep them well informed of decisions and particularly of the child's death.

In some situations families may prefer to care for their child at home. This may be when the focus of care becomes palliative and some period of time at home is anticipated. Occasionally the family may elect to have intensive treatment withdrawn at home or take the child's body home after death. Careful communication and arrangements, according to the circumstances, need to be made between the primary health care team, the children's community nursing service or local palliative care team and their local paediatric unit. This will ensure that there is adequate support available, good continuity of care and that plans for a time of crisis are understood by all those involved.

Levels of community services still vary in different parts of the country but families will need 24 hour access to paediatric care and advice and local teams will need 24 hour access to advice and expertise in symptom management in palliative care. Families also need to know that they have a hospital bed available at any time if they need it.

³⁷ No matter how careful the diagnosis during life, the EAC-RCPCH believes that a request for a post mortem is always appropriate. Information from postmortem consolidates and confirms the diagnosis during life providing certainty for the parents and the clinical team. The results should be given to the parents as soon as it is possible.

3.4. Resolution of different opinions

Where there is a lack of agreement within the team or between the team and the family it is important to analyse its origins. It is possible that these reflect different understandings of the issues and that more time to consider them and better communication will resolve the tension. If there is anxiety about the degree of certainty behind the medical facts it should be considered whether any further investigation might help to resolve this. Input from religious advisors or other important sources of support to the family may be helpful. However, personal beliefs may dictate that some individuals decide in a particular way whatever the circumstances.

Unanimity on the part of the Health Care Team is not essential (see 3.3.1). **Resolving a difference of opinion between the team and the family is essential** and may occasionally require additional input. Under these circumstances the family should still be fully supported by the team.

3.4.1. Medical Input

The involvement of another senior clinician may help in the communication of bad news or in decision making. This could come from within the team if the main issue is one of uncertainty, but if there is a more fundamental disagreement between the family and the team or there has been an erosion of trust, an expert opinion from outside the unit/hospital may be preferred. This could be organised by the consultant responsible for the care of the child. To secure greater confidence in the independence of the second opinion, the family may wish to arrange this themselves with the help of their general practitioner. The family should be at liberty to change clinician and move to another consultant if this is possible.

3.4.2. Legal Input

In most cases, with effective communication and adequate time, the health care team and parents will come to agree. If this does not prove possible and other efforts to resolve the situation are not successful then the courts should be consulted. Every NHS Trust has a legal adviser and it should be possible to obtain legal advice through the hospital management structure. Another source of advice is the CAFCASS Legal Services (Children and Family Court Advisory and Support Service) can be telephoned for advice which will help clarify the need for court involvement. In the rare situation that court assistance is deemed necessary, the parents or their representative should be notified as soon as possible of such intended action. Legal support for medical matters would usually be sought from a judge in a High Court. At such a hearing parents must be able to express their own views and seek alternative opinion.

3.4.3. Clinical Ethics Committees

The number of Clinical Ethics Committees established in the UK is increasing. The function of such committees may include discussion, analysis and advice on individual cases as well as contribution to policymaking, teaching, training and research.

In our opinion the factors which are likely to result in best decision making in individual cases are factual knowledge of the problems and of the circumstances of the patient concerned and good relationships between the parties involved. Ethics Committees may be too remote from the individual case to understand all the nuances involved, too ready to reach a consensus and may lack an innovative approach to problems. There are fears that they may limit freedoms and create further bureaucracy around patient care. However they may bring significant analytical skills and may have important mediation and conciliatory functions and may serve to protect patients' rights.

If Clinical Ethics Committees are to be used to discuss cases in a proactive fashion they need to be easily convened and to develop supportive and educational functions.

Various models of functioning are possible:

- 1) It may be obligatory to consult a committee and to accept its recommendations;
- 2) It may be obligatory to consult but not to accept recommendations, and
- 3) Both consultation with the committee and the acceptance of its recommendations are optional.

In practice models 1 and 2 are seldom used and 3 is the most appropriate for individual case discussion.

Any UK Clinical Ethics Committee needs to retain its independence so as to secure its moral integrity. It is not clear how this is to be protected in the current Hospital and Primary Care Trust since both may be considered to have some financial interest in the decisions made. It is not clear how these tensions will develop in the future or what means may be used to reduce them. Whichever model of Clinical Ethics Committee is created, it remains the case that legal and professional responsibility for decision making still rests with the consultant in charge of the case.

It is possible that Clinical Ethics Committees may have a role if there is an appeal against a decision to withdraw or withhold treatment made in another Trust and an independent analysis of the case is required.

4. Bereavement

4.1 Families

The death of a child is one of the most devastating experiences that a parent can have and the quality of care at the end of life and after the child's death can have a major impact on the family's grieving.³⁸

Each hospital should have a policy in place for when a child dies and provide information which should be readily available for staff which includes details about asking for post mortems, the needs of different cultures and the provision of mementos for the family. There should also be information which can be given to families on the immediate practical details they will need for registering the death and making funeral arrangements and also for the future on how they may feel and how they can access support.

It is important to provide follow-up for parents after the death of a child. Sometimes due to the pressures of acute medical care this is promised but not fulfilled. Sometimes it is helpful for families if this is undertaken by a home visit. Contact between 1-2 months later gives the opportunity to discuss the results of a post mortem or investigations that may shed more light on the circumstances surrounding the death, to answer families' medical questions and to explore their feelings. Some teams are able to offer continuing, but gradually diminishing contact with acknowledgement of special anniversaries such as the child's birthday and date of death.

Grief is a normal reaction to bereavement and sometimes professionals seek to medicalise grief and intervene inappropriately. Many families will find their own support in different ways and at different times. Families should be given access to information from both staff and voluntary organisations to enable them to make choices from the support and services available. More counselling from support organisations or other forms of therapy can be offered to families requesting such help.

4.2 The Health Care Team

Like the parents, individuals in the health care team will experience a wide range of emotions, both in the short term and over time. Work pressures can interfere with the resolution of these issues and failure to address them can lead to stress, sickness, lowered morale and divisions

³⁸ Chiswick M. "Parents' end of Life decisions in neonatal practice" *Arch. Dis. Child* (2001) **85**: F1-3.

McHaffie HE, Laing IA, Lloyd DJ "Follow-up on bereaved parents after treatment withdrawal from newborns" *Arch. Dis. Child* (2001) **84**: F125-128.

within the team. All staff may need support but many may not know how to acknowledge or approach this need. Discussion sessions can be helpful but they may be complicated by questions of status, social taboos or defensive behaviour and protection. Senior doctors may find it difficult to share their stresses and uncertainties with trainees and nursing staff. Certain groups may be specifically vulnerable e.g. night staff. Each person has different needs and they may gain support from more senior staff, professional support workers, friends, partners, chaplains and others. Some are helped by maintaining contact with the families and by going to the funeral although both of these can also bring new stresses. Even with a formal support network the appropriate individuals are not always available when they are most needed.

Dealing well with these issues will have a beneficial effect on staff morale and should reduce staff sickness and turnover. Management need to be aware that resources allocated in this area will support their staff, benefit the organisation and improve health care delivery.

5. The Future

5.1. Training

All clinical staff and nurses should have access to continuing education in communication, ethics and the subject of withdrawing and withholding care. Such areas now have a more prominent role in medical and nursing curricula. It has been recognised in the GMC Guidance on *Training Tomorrow's Doctors* and in a scientifically based education it is essential that the psychological and spiritual dimensions of care are fully considered. Hospitals may also consider having an educational clinical ethics forum that periodically meets to review difficult cases³⁹, and child bereavement organisations and parent support groups should be used in providing some of this training. Finally the assessment of ethical issues, communication, knowledge and approaches should continue to form a mandatory part of the assessment of competence in clinical training.

5.2 Resources

Although clinicians do not and should not give paramount importance to resources in decisions about care, such considerations have always entered into discussions about treatment options. With limited available money in the NHS, offering expensive treatment inevitably uses funds that may have been better used elsewhere. The EAC-RCPC do not feel that decisions about the sort of child who would be offered intensive care should be resource motivated but should be determined by whether such care was appropriate.

5.3 Research/audit

It is vital for units involved in work where withholding or withdrawal of life sustaining treatment is practised not only to conduct self-audit over the outcome of their care but also to obtain feedback from the affected families.⁴⁰ As perspectives may change with time, such surveys should aim to be continuous, over a period of years.

How can children's competence, their ability to cope with distressing news, and their ability to make decisions be assessed? In many British hospitals varied ways of communicating with

³⁹ Larcher VF, Lask B, McCarthy J, "Paediatrics at the cutting edge: do we need clinical ethics committees?" *J Med Ethics* (1997)**23**: 245-249

⁴⁰ Alderson P, Montgomery J *Health Care Choices – Making Decisions with Children*. London: Institute of Public Policy Research, 1996. Alderson P. *Children's consent to surgery*. Buckingham: Open University Press, 1993.

⁴¹ Saigal S et al. *Pediatric Research Abstracts*. Abstract 225, (1995)**37**:40A. and Abstract 1654, (1996)**39**:378A.

children, beyond cognitive and strictly verbal approaches, are being used⁴¹. These need to be more widely reported and explained.

Research has been done and more is needed amongst disabled people to determine what degrees of disability they would think of as too burdensome to risk for others. Undoubtedly this is an area where it will be difficult to reach a consensus as the burden of disability depends on different perceptions.

The UK Census⁴² has confirmed that one in ten children are classed as from minority ethnic groups and therefore decisions on the withdrawal of treatment need to be underpinned by an understanding of cultural 'diversity'. This is a relatively under-researched area.

5.4. Clinical Ethics Service

While there is agreement that support, guidance, teaching and training in these sensitive areas are required for all staff there is as yet no consensus as to how these aims are to be achieved and how the impact of providing ethical support is to be evaluated. A greater interest in qualitative research and the interface between the Humanities and Medicine may provide the necessary impetus and tools to accomplish this task. The establishment of a UK Clinical Ethics Network⁴³ will provide a forum for exchange of ideas, methodologies and protocols and also support for those attempting to establish, maintain or validate their service.

⁴² Sheikh A, Gatrad AR. "Children and Young Families". In *Ethnicity, Health and Primary Care*, Ed. Kai J. Chapter 16 p. 151. Oxford: Oxford University Press, 2003

UK Census England and Wales www.pro.gov.uk

⁴³ www.ethics-network.org.uk

6. Conclusions

There are some circumstances in which the continuation of medical attempts to cure are either manifestly futile or inflict unbearable suffering on the child. Professionals, trained to restore health, often feel that they have failed patients whose problems persist despite active treatment. However, in some circumstances, to continue life sustaining treatment is to offer care that is no longer in the child's best interest.

Appropriate withdrawal of treatment will depend on accurate knowledge of the condition and sound inter-relationships with and around the child. Good judgement will usually involve consultation. Conflicting emotions can affect the balance of both parental and professional judgement. The availability of professionals who can address this conflict could be helpful in explaining and defusing areas of potential tension. Decisions should never be hurried and there should always be respect for the child's life and a responsibility to relieve suffering. The lives of those with severe disabilities, whether physical or mental, are to be highly valued. All who relate to those with disability should offer them the best personal, and professional care.

