

FOREWORD

It is now more than 18 years since the late Professor David Baum wrote the foreword to the first *Withholding and Withdrawing Life Saving Treatment in Children* document. Since then the practice of paediatrics has changed radically. We are now seeing increased survival rates for infants born between 22 and 25 weeks gestation, new gene therapies stretching the boundaries of possibility, and advances in paediatric surgical techniques unimaginable in the last millennium.

Against this backdrop, we are in an era of ubiquitous access to the internet and widespread use of social media. Children, young people, their parents and carers have very different knowledge and expectations of a condition and its treatment. Children and young people rightly expect to be fully involved in decisions about their treatment options wherever this is feasible and we must be able to communicate those options clearly and honestly.

In this extraordinary world of medical miracles, one thing has not changed; the complexity, challenge and pain of that most difficult of decisions: is the treatment we are providing no longer in the best interests of the child? There is no technology to help us here—only guidance, discussion, and adequate time and information for truly shared decision making. Our commitment to the child's best interests must start before birth and continue through to palliative and end of life care. Even after death, a duty to provide bereavement support for parents and siblings is the natural conclusion to the difficult decisions we have made with them in the preceding weeks and months.

This latest guidance on arguably the most difficult aspect of paediatric care has updated the decision making framework and incorporated more extensive advice on the direct involvement of children and young people. It also takes account of the broader possibilities flowing from developments in paediatric palliative care.

This is a live document and a starting not an end point for discussion and learning, I commend it to you.



Hilary Cass

President Royal College of Paediatrics and Child Health (RCPCH)

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Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice

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PREFACE

The first edition of the Royal College of Paediatrics and Child Health (RCPCH) document 'Withholding or Withdrawing Life Saving Treatment in Children: A Framework for Practice' was published in 1997 and was one of the first documents produced by the newly-formed College. The first edition followed a series of workshops, public meetings and discussions in the Ethics Advisory Committee. There was consultation with a wide range of clinicians, representatives of faith groups and parents' groups and from individuals with disabilities themselves.

Given the difficult and emotive nature of the subject, and the significant number and differing views of those consulted, the original document acknowledged the impossibility of achieving total consensus, but did identify common ground on which a framework could be built. The framework document was widely used; it did inform constructive debate and provided clarification in this difficult and emotive area.

The second edition, published in 2004, reflected changes in practice and new legislation but retained the same ethical and legal principles as the first.¹ Its title was changed from 'life-saving treatment' to 'life-sustaining treatment' to reflect the fact that the treatment that is often given in these circumstances is not curative but supportive.

The need for a revision of the document has been considered over the past 2 years by the Ethics and Law Advisory Committee of the RCPCH (ELAC-RCPCH). Once again, we have consulted those who have used the document and have incorporated comments from individuals and groups, both in the UK and elsewhere. As before we have attempted to synthesise differing views and values in reaching a consensus. We were also mindful of the change in emphasis in decision making with individuals with life-limiting conditions, as exemplified in the General Medical Council (GMC) document: 'Treatment and care towards the end of life: good practice in decision making'.² We have incorporated relevant case and statute law decided or enacted since the last edition. We have also taken into account developments in palliative care provision and the growing availability of ethical and other support in decision making, as well as issues that have arisen in response to the two previous documents. In particular, we have replaced the five criteria that were previously used to identify situations in which limitation of treatment might be discussed with a more formal classification based on quantity or quality of life. We have included a category that formally acknowledges the wishes and preferences of those young people who are able to make decisions for themselves, albeit with the support of their families and professionals.

We accept that decisions to withhold, withdraw or limit life-sustaining treatment in children with life-limiting or life-threatening illness may still prove contentious, difficult and emotive. Once again, we have attempted to provide a framework for practice that is not prescriptive and that attempts to recognise the interests of the child both in his or her own right but also as part of their family. We accept that determining the best interests of an individual child is complex; nevertheless it remains a fundamental consideration in the kind of situations to which this document refers.

We emphasise two important points so as to avoid confusion:

1. This document sets out circumstances under which withholding or withdrawing life-sustaining treatment might be ethically permissible—NOT circumstances under which such treatment *must* certainly be withheld or withdrawn.
2. The document describes situations in which individual children should be spared inappropriate invasive procedures—NOT *types* of children to whom appropriate procedures should be denied.

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Executive summary

This document, like the two editions that preceded it, is intended to provide an ethical and legal framework for making decisions to limit life-sustaining treatments (LST) in life-limiting and life-threatening conditions in children. It has been revised to reflect both changes in the scope and availability of advanced technologies and in the emphasis and application of ethical and legal principles to decision making. It sets out circumstances under which withholding or withdrawing life-sustaining treatment might be ethically permissible—NOT circumstances under which such treatment *must* certainly be withheld or withdrawn. In particular it describes situations in which individual children should be spared inappropriate invasive procedures—NOT *types* of children to whom *appropriate* procedures should be denied. It takes account of the wider interests of children and of families and their greater involvement in the decision-making process. It also reflects the increasing availability of children's palliative care services and of other support services for all those involved.

Despite increased options for the provision of end-of-life care, many deaths still occur in hospital settings following decisions to withhold, withdraw or limit LST.

The Royal College of Paediatrics and Child Health (RCPCH) acknowledges the sensitive and challenging nature of such decisions for all concerned. It respects the sincerely held differences in values and beliefs and the diverse cultural factors that impact on the process and reaffirms the need to achieve a consensus within an ethical and legal framework.

The legal considerations and the basis for making decisions for withholding and withdrawing LST are grounded in both statute and case law. The guiding principle remains that of determination of the child's best interests, albeit with greater consideration of the interests of families and of their rights.

The ethical basis for withholding or withdrawing LST involves consideration of a child's best interests. It too reflects a change in emphasis that places greater recognition of children's rights to be actively involved in decision making, whilst considering broader family interests.

The RCPCH reaffirms the application of these ethical and legal principles to the process of decision making. Hence all members of the child health team, in partnership with parents,

have a duty to act in the best interests of the child. In so doing the RCPCH is mindful of the obligation to take account of and respect the value that children and young people and their families place upon their lives. Nevertheless treatments that are no longer in the child's best interests may be withheld, withdrawn or limited. This applies to treatments that merely sustain life but that neither restore health nor confer overall benefit.

Increasingly children with life limiting illnesses will live beyond their 16th or 18th birthdays. Arrangements for transition should accord with best practice and be subject to age-appropriate or age-determined legislation. Limitation of treatment decisions should be in accordance with age-related ethical and legal guidance.

The RCPCH believes that there are three sets of circumstances when treatment limitation can be considered because it is no longer in the child's best interests to continue, because treatments cannot provide overall benefit:

I When life is limited in quantity

If treatment is unable or unlikely to prolong life significantly it may not be in the child's best interests to provide it. These comprise:

- A. Brain stem death, as determined by agreed professional criteria appropriately applied
- B. Imminent death, where physiological deterioration is occurring irrespective of treatment
- C. Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by LST confers no overall benefit.

II When life is limited in quality

This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:

- A. Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits
- B. Burdens of the child's underlying condition. Here the severity and impact of the child's underlying condition is in itself

sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life

- C. Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life.

III Informed competent refusal of treatment

Adults, who have the capacity to make their own decisions, have the right to refuse LST and to have that refusal respected. So an older child with extensive experience of illness may repeatedly and competently consent to the withdrawal or withholding of LST. In these circumstances and where the child is supported by his or her parents and by the clinical team there is no ethical obligation to provide LST.

In situations other than those described, or where there is uncertainty about the nature of the child's condition or its likely outcome, treatment should be continued until greater certainty is possible. The degree of certainty should be proportionate to the gravity of the decision to be taken. Adequate time must be allowed to collect evidence and this may entail obtaining second opinions from clinicians with appropriate skills, knowledge and expertise of the child's condition.

Decisions to limit treatments—or what treatments should be given—should be made by clinical teams in partnership with, and with the agreement of, the parents and child (if appropriate). They should be based on shared knowledge and mutual respect. Where possible they should be made in advance of acute events in the form of care plans and be available for all relevant parties.

A wide range of treatments may be withheld or withdrawn if it is in the child's best interests to do so. They include cardiopulmonary resuscitation, clinically assisted nutrition and hydration as well as mechanical ventilation. Limitation of treatment agreements are increasingly used because of the greater range of options in decision making they offer.

Decisions to limit LST do not constitute withdrawal of care. Treatments, including palliative care, that are intended to relieve suffering of the child and his or her family produced by illnesses and their treatments or by disability, are ethically justified. They

should be offered early in the course of life-limiting or life-threatening illness.

Any discussion about organ donation from a child who is approaching death must be handled with skill and sensitivity. All decisions about organ donation should be made entirely independently from those regarding withholding or withdrawing life-sustaining treatment.

The primary consideration in decisions to limit LST is whether or not treatment is in the child's best interests. However, decisions about treatment options may be increasingly complicated by resource constraints. Healthcare teams may not be justified in providing treatments that are highly expensive or of limited availability and that appear to offer little benefit to the child. Ideally, such decisions should be based on clear and consistently applied policies developed at institutional, local or national levels.

Communication, within healthcare teams and with parents and children is important and should also include those in the community who also have a duty of care to the child. Communication of information should be in a form and given at a pace that is appropriate for children and families and takes account of any special needs they have.

Because of the sensitive nature of the discussions to limit treatment, differences of opinion, often based on sincerely held beliefs and values, may occur between any of the parties. It is important to understand and attempt to resolve these differences using recognised support services for example, Patient Advice and Liaison Service (PALS), Clinical Ethics Services, chaplaincy. In cases where differences cannot be resolved by these means legal intervention may be necessary with courts as the ultimate arbiter of best interests.

Professional duties and responsibilities do not cease when a child dies and the provision of bereavement support services for families and support for staff are increasingly recognised as necessary parts of the grieving process for all involved.

All clinical staff should have access to continuing professional training and education in communication skills, ethics and the issues raised by decisions to limit treatments. The process should be audited to ensure that the physical and emotional needs of children and their families facing such decisions are met.

1. INTRODUCTION

The key purposes of medicine are to alleviate suffering, restore health, sustain life and prevent disease. In paediatrics, members of healthcare teams work in partnership with children and their parents to achieve these objectives. The healthcare team, formed of healthcare professionals, 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 should in all cases work closely with the parents and the child. The ethical and legal rationale for all treatments, present and future, is that they should be in the best interests of the child.^{1–3}

The application of technology has led to the development of treatments that can sustain life in circumstances where this was previously impossible. But some treatments may neither restore health nor confer overall benefits to the child. They, and the nature of the condition which the child has, may produce pain and suffering for the child and their families that may be hard for them to bear. This leads to dilemmas as to whether treatments that are technically feasible *should* be used.

Some of the most challenging and emotionally complex decisions arise in relation to withholding, withdrawing or otherwise limiting treatment that has the potential to sustain life, but which imposes burdens or has serious impacts. Such decisions inevitably involve value judgements about what should be provided; there may be legal uncertainty about what is permissible. They may have to be made in a context where absolute certainty over outcomes does not exist. Whatever the outcome of the decision-making process, children and their families need high-quality treatment that provides them with comfort and support and that is delivered with appropriate expertise.

Despite the increasing availability of guidance from professional and other bodies, many healthcare professionals, patients and families in these circumstances continue to need practical help in making decisions.

The purpose of this document is to provide a framework in which decisions can be made that are in the best interests of the child and in accordance with the principles of good medical (clinical) practice.³ This document primarily sets out to provide help and guidance for members of healthcare teams, but we hope that it may also increase the understanding of parents and families and others who confront these decisions. It conforms to established ethical principles as they apply to children and their families. It is also consistent with current UK law; but it is neither a legal text nor a substitute for seeking legal advice when it is appropriate to do so.

This document acknowledges that absolute agreement in decision making may be neither practical nor achievable, but recognises the obligation to seek as much common ground as possible, whilst accepting there will be sincerely held differences of opinion.

Decisions to withhold, withdraw or limit life-sustaining treatment involve a change in the goal of care from cure to symptom relief. This document outlines the circumstances in which such decisions might be appropriate and in which end-of-life care might be appropriate. The latter includes palliative care that is focussed on relief of symptoms and the provision of psychological, social and spiritual support for children and their families so as to maximise the quality of life that remains.

This document, whilst remaining grounded in the ethical and legal principles set out in the 1997 and 2004 editions, also reflects changes in emphasis in the decision-making process and the provision of palliative care that have occurred in this period.

2. BACKGROUND CONSIDERATIONS

2.1 Definitions

This document especially applies to children with life-limiting or life-threatening conditions. Life-limiting or life-shortening conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Life-threatening conditions are those for which curative treatment may be feasible but can fail.³ These will include: -

- children with advanced progressive incurable disease
- children whose death is expected in the foreseeable future
- children in whom there is a risk of death from a sudden acute crisis in the condition
- children in whom sudden catastrophic events have produced a life-threatening situation
- children in whom the prospect of survival is small, for example, some extremely premature infants

Life-Sustaining Treatments (LSTs) are those that have the potential to prolong life. They may include experimental therapies that are not validated by research, as well as more conventional treatments such as Cardiopulmonary Resuscitation (CPR), mechanical ventilation, intravenous inotropes, antibiotics, renal dialysis and Clinically Assisted Nutrition and Hydration (CANH). Evidence for burdens and benefits of LST in specific individual circumstances may not always be available.

There are several different types of decision made about LST. Treatment that has not been commenced may be withheld. Alternatively, decisions may be made to withdraw treatment that has already started, or to impose limits on that treatment (for example by agreeing on a maximum level of respiratory or cardiovascular support that will be provided).

Palliative care (see ‘Palliative care’) for children and young people with life-limiting conditions is an active and total approach to care that continues from the point of diagnosis or recognition throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of respite care for children and families and care through death and bereavement.⁴ Palliative care can be given alongside active interventions; it is not confined to situations where a decision to withhold or withdraw active treatment has been made.

Best Interests. Throughout this document the term ‘best interests’ has been used in the sense used in law (the five point welfare check list of the Children Act 1989; the 9 point check list of the Mental Capacity Act 2005 as applied to over 16-year olds) and in published professional guidance (GMC End of life Care 2010; GMC 0–18 years: guidance for all doctors 2007). No single formula applies but determination of clinical best interests involves balancing benefits and burdens (of whatever type) of treatments and outcomes, whilst considering the ascertainable wishes, beliefs and values and preferences of the child and their family, the cultural and religious views of the latter, the views of those providing care for the child and what choice is least restrictive of future options.

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

Around 3700 children (defined as those aged between 28 days and 19 years) and 2100 neonates still die each year in England alone.⁵ In comparison with adults, a greater proportion of children who die in hospital do so within the intensive care setting, and this number is increasing.⁶ Hence many children die in an environment of aggressive organ support made possible by

technical developments such as Extra Corporal Membrane Oxygenation (ECMO) or Berlin heart devices, or by organ transplantation or multiple stem cell therapies. The range of therapeutic and palliative options for children with life limiting conditions has expanded, so that some interventions, with relatively high acute impacts for children are now provided, when this was previously not the case. Increasingly children with life limiting conditions live beyond their 16th to 18th birthdays so that arrangements for the transition to adult services for ongoing care and support is important.

Since the production of the first edition of this document in 1997 there has been increasing collaboration between palliative and intensive care services and adult services, with the intention to optimise the care of children with life-limiting or life-threatening conditions. Although the challenges in providing high-quality care in the differing settings of the intensive care unit and the home or hospice remain, the recent production of shared guidance in managing some situations is a positive development (see for example, the recent Association for Children's Palliative Care (ACT)/Together for Short Lives (TfSL) document, 'A care pathway to support extubation within a children's palliative care framework'⁷).

End-of-life practice in UK PICUs has remained fairly typical of the Northern European approach, as demonstrated in the Eurydice studies of 'Forgoing life-sustaining treatments in children'.⁸⁻⁹ Most deaths follow withdrawal or limitation of LSTs, rather than failed resuscitation.¹⁰ Overall this proportion has increased in recent years.¹¹⁻¹² A similar pattern is seen in the neonatal intensive care environment.¹³

There is growing acceptance that such practices are ethically acceptable provided that there is no overall benefit in continuing treatment.¹⁴⁻¹⁶ In the US, guidance has been produced that considers forgoing medically provided nutrition and hydration, but such specific guidance has yet to be developed for the UK.¹⁷ Other professional and regulatory bodies have produced guidance in decision making towards the end of life, though they are more generic and not specifically focused on the child and his or her family.²⁻¹⁸

However, all accept the principle that medical treatment can legally and ethically be withdrawn when it is unable to provide overall benefit, when it is no longer in the patient's best interests, or if the patient has refused it.²⁻¹⁸

Recognition that aggressive and invasive therapy may not be in an individual child's best interests can be a gradual process, but is increasingly informed by timely open discussion between all parties involved and in advance of acute episodes of deterioration. Defining a child's best interests and whose views should count most, may also be a source of disagreement. It has occasionally been necessary to refer cases to court for resolution. The outcome of some cases and the principles underpinning individual judgments which may help with decision making are set out in 'The legal framework'. Recent practical experiences in end-of-life decision making with children and families have demonstrated that potential conflicts can be avoided by frank, open and considerate dialogue and the early involvement of supportive groups from hospitals and the community (see 'Bereavement').¹⁹

2.3 The legal framework

This section provides an overview of the current law that would apply to end-of-life decision making. It is neither a comprehensive account of statute and common law, nor is it a substitute for obtaining legal advice in the individual case. Each case is unique and should be considered and decided on its own individual facts.

All healthcare professionals have a legal duty of care towards their patients and are bound to act within the framework of the law. The law articulates standards of behaviour by prohibiting certain actions and allowing others. Any practice or treatment given with the primary intention of causing death is unlawful.²⁰

All cases relating to withholding or withdrawing LST are decided in accordance with the common law, ie case law. The courts will consider and decide each case on its own facts.

2.3.1 Statutes

A. The Children Act (England and Wales—1989 and 2004; Scotland—1995)²¹

The Children Act provides an overall statutory framework for delivery of children's services, and the rights and responsibilities of parents. It makes no specific provisions for withholding or withdrawing treatment but enunciates important principles that underpin practice, the most relevant of which are:

- ▶ A child's welfare is of paramount consideration when making decisions about the child.
- ▶ Particular regard should be paid to the ascertainable wishes and feelings of the child and any harm which the child has suffered or is at risk of suffering.
- ▶ Parental rights and duties must be exercised in the child's best interests.

B. The United Nations Convention on the Rights of the Child²² and the Human Rights Act 1998²³

The United Nations Convention on the Rights of the Child (UNCRC) applies to all children and young people under the age of 18 and was ratified by the UK in 1991. Whilst it cannot be directly applied in UK courts, ratification means that the UK government is bound to honour it and to make all laws, policy and practice applying to children compatible with it.

The Human Rights Act (HRA) 1998 incorporates and gives effect in the UK to the rights and freedoms guaranteed under the European Convention on Human Rights (ECHR). The most relevant convention rights with respect to decisions to limit LST in children are:

- Article 2: the right to life and the positive duty to protect it
- Article 3: the prohibition of inhuman and degrading treatment
- Article 5: the right to liberty and security of the person
- Article 8: the right to respect for private and family life
- Article 9: the right to freedom of thought, conscience and religion
- Article 14: the prohibition of discrimination in respect of enjoyment of the other rights

Although there is a positive obligation to protect life, in certain cases treatment can be withheld or withdrawn, where it is in a child's best interests to do so, even if this will result in the child's death. When tasked with intervening in disputes which have arisen over the withholding or withdrawing of treatment, judges seek to balance the duty to respect and protect life (Article 8) against the duty not to inflict inhuman and degrading treatment (Article 3), whilst attempting to respect the provisions of Articles 8 and 9.

C. The Mental Capacity Act 2005 and the Adults with Incapacity (Scotland) Act 2000²⁴

These Acts provide the legal framework for acting and making decisions on behalf of individuals aged 16 and 17 ('young persons'), who lack the mental capacity to consent to treatment and/or make particular decisions for themselves.

Decisions must be made in the best interests of the young person who is assessed as lacking capacity to consent by the

healthcare professional responsible for the young person's care in accordance with criteria set out in the Acts.

Young persons will lack capacity to consent if they are unable to (a) understand the information relevant to the decision, (b) retain that information, (c) weigh that information as part of the decision-making process and (d) communicate the decision reached (whether by talking, using sign language or any other means).

When assessing the young person's best interests, the healthcare professional must consult with those involved in the young person's care and anyone interested in their welfare—if it is practical and appropriate to do so—in order to help them reach a decision on best interests. The extent to which the young person's parents are consulted will depend on the particular circumstances and healthcare professionals will need to take care not to breach the young person's right to confidentiality.

D. The Equality Act 2010²⁵

The Act brings together many separate pieces of legislation to provide a single legal framework to protect the rights of individuals and to provide equal opportunities for all regardless of age or disability. It protects people from discrimination in the work place, education and the wider society. It protects disabled people from discrimination and unfair treatment arising directly from their disability and indirect discrimination arising from the application of a rule, policy or practice that applies to all but is particularly disadvantageous to those with a particular disability, compared with those who do not have it and cannot be shown to be justified as being intended to meet a legitimate objective in a fair, balanced and reasonable way. The Act also provides protection against victimisation or harassment.

E. Children and Families Act 2014^{25a}

The Children and Families Act is a recently enacted, wide-ranging piece of legislation intended to improve services for key groups of vulnerable children, including those with disability. An important provision is the ultimate replacement of Statements of Educational Need by person centred, co-ordinated Education, Health and Care (EHC) plans designed to meet the child's educational health and welfare needs. The general principles and matters to be considered in EHC assessments and plan formulation are similar, albeit in different clinical circumstances, to those involved in the formulation of advance care plans. The process of making decisions to limit LST will need to take due account of any relevant EHC plans.

2.3.2 The child and young adult

The Children Act 1989²¹ requires that particular regard must be given to the ascertainable feelings and wishes of the child, in the light of the child's age and understanding, as well as any harm which the child is suffering or at risk of suffering. Under the terms of the Children Act. Health professionals and parents must always seek to involve the child in any decisions being made about them, in a way that they can understand. This is particularly relevant in cases involving LST and decisions to discontinue it.

The Mental Capacity Act 2005 and the Adults with Incapacity (Scotland) Act 2000,²⁴ though applying to those (aged 16 and over) who lack capacity to consent, does not permit those under 18 to make advance decisions (also known as advance directives) or create a Lasting Power of Attorney (appointing another to make health and welfare decisions on their behalf).

Unless given in a genuine emergency, all medical treatment requires consent that is informed and freely obtained from a

person who has capacity. Proposals to change the goals of treatment or to withhold, withdraw or limit LST also require consent.

When involved with children or young persons, the following general principles apply:

- ▶ In England and Wales, children aged 16–17 years are presumed to have capacity to consent to treatment,²⁶ but they cannot refuse treatment that is considered to be in their best interests. Legally, a parent can consent to treatment even if a competent young person refuses treatment.
- ▶ In Scotland, children over 16 years may both consent and refuse all treatments provided they have capacity.
- ▶ Where a child (young person) of 16–17 years lacks capacity, consent can be given by a person who holds Parental Responsibility (PR).
- ▶ Children under 16 may consent to treatment (in their best interests) if they are capable of fully understanding the implications of their decision.²⁷ The Gillick test is commonly used to ascertain whether a child (aged 16 years or younger) is able to consent to his or her own medical treatment, with or without the need for parental consent and/or knowledge. For the child to be Gillick competent, the child must have sufficient maturity and understanding to take a decision of the seriousness in question.
- ▶ A child may refuse LST where parents and clinicians agree with that refusal. However, where there is no such agreement, the child's refusal may be overridden by those with PR or by the Court if it is considered in their best interests to do so. The Children's Act and the UNCRC place emphasis on involving individual children, in accordance with their age and capacity, and giving due weight to their views in making informed determination of what is in the child's best interests.

2.3.3 Parental responsibility

A. Rights, duties and power

The meaning and scope of PR is set out in the Children Act 1989. PR refers to the rights and responsibilities parents have in respect to their children. This includes decisions relating to medical care and its withdrawal (subject to such decisions being made in the child's best interests).^{28 29} PR is one of the key principles of the Act; there are a number of ways by which one can acquire PR under the Act.

- ▶ For children whose births were registered after 15 April 2002 in Northern Ireland, from 1 December 2003 in England and Wales, and from 4 May 2006 in Scotland, PR rests with both parents, provided they are named (at the time of registration) on the birth certificate, regardless of whether they are married or not.
- ▶ A child's biological mother automatically has PR.
- ▶ In all other cases, a father does not have PR unless he was married to the mother at the time of the child's birth, or has entered into a PR agreement with her, or obtained a court order granting him PR.

It is good practice for both parents to be fully involved in decision making as far as possible, whether or not the father has PR.

Other individuals can obtain PR by court order, or by being appointed as a guardian on the death of a parent, for example, a local authority, grandparents, foster carers, etc. There has been extension in relation to PR by the Children and Families Act 2014^{25a} for fathers or second female parents named in Child Care arrangement Orders (previously referred to as residence and contact orders) and it is important therefore that you establish as is reasonably possible who has PR responsibility. If there is doubt, legal advice should be sought.

Generally the consent of one parent is sufficient to provide authority for medical treatment.³⁰ If, however, there is disagreement between parents as to the child's or young person's best interests, an application should be made to court for a determination as to best interests.

There are rare circumstances, defined by case law, for example, ritual circumcision, for which the consent of both parents is necessary.³¹

Consent to the withholding or withdrawal of treatment may be given by anyone who holds PR. However, where PR is shared, if there is parental or other opposition, parental equivocation or doubt as to parental capacity or a disagreement as to what is in the child or young person's best interests, an application should be made to court for a determination as to best interests.

A parent aged 16 and above is presumed to have capacity, unless shown not to satisfy the test of capacity under the Mental Capacity Act (MCA) 2005. A parent under 16 is assessed by reference to the Gillick test (see 'The child and young adult'). If a parent lacks capacity, the parent will not be able to give valid consent and an application will need to be made to court for treatment to be lawfully given.

B. The interface between parental interests and wishes and professional duties

The extent to which a parent's wishes are determinative have been considered and set out in common law in a way which is compatible with the ECHR. A number of basic principles can be derived from these cases:

- ▶ It is essential to involve parents in decision making.³²
- ▶ Where intractable or irreconcilable differences of opinion arise between parents and healthcare professionals, the court's intervention should be sought for a determination on whether the proposed treatment, or withholding or withdrawal of treatment, is in the child's best interests.³²
- ▶ Whilst the court will have regard to the views of parents, the extent to which these will be determinative will depend on the court's assessment of that view. The court is the final arbiter in such circumstances and it may overrule the decision of a parent.

C. When parental and professional interests are in conflict (see 'Practical aspects of decision making' and 'Bereavement' for practical details of management)

Most decisions relating to healthcare, including those pertaining to the limitation or withdrawal of treatment, are reached in consensus with the family and, where appropriate, the child. Infrequently there may be disagreement either within the treating team or with the child and/or child's family over a child's best interests. Such disagreement may be borne of miscommunication or differences in genuine and deeply held beliefs.

Good practice requires ongoing discussion between relevant parties to resolve disagreements. Clarification of the facts, by obtaining second medical opinions or clarification and analysis of the ethical issues involved by clinical ethics services and others, may be helpful, as may the use of mediation techniques. Wherever possible these should be used before referral to court is made. If a matter is referred to court, the court will wish to know what attempts have been made—and by whom—to resolve conflicts.

2.3.4 The role of the courts in end-of-life decision making

If agreement cannot be reached between parents, or those with PR, and healthcare professionals, legal advice should be sought from specialist healthcare lawyers. Taking legal advice, of itself, does not necessarily mean that court proceedings will follow.

The court has inherent jurisdiction to grant a Declaration making it lawful for healthcare professionals to withhold or withdraw LST notwithstanding the absence of parental consent if this is deemed to be in a child's best interests.³³

The court must exercise independent and objective judgment on the basis of all the evidence and consideration will be given to, amongst other factors:

- ▶ The likely quality of future life for the child with and without treatment.^{34–36}
- ▶ The intolerability of treatment or outcome.
- ▶ The relevant clinical considerations.^{37 38}
- ▶ The pain or suffering caused by the treatment.
- ▶ The pleasure a child may derive from its current life including the child's awareness. The court will conduct a balancing exercise in which all relevant factors are weighed. The court will assess the benefits and burdens of giving or not giving potential treatments and of maintaining or withdrawing certain forms of treatment in order to assess best interests.^{39–41}

The court's approach in end-of-life decisions

In reaching decisions about withdrawing or withholding LST, the court adopts a strong presumption in favour of preserving life. The court will balance a number of legal principles, for example, the sanctity of life, the prohibition against inhuman and degrading treatment, the freedom of thought, conscience and religion and the right to family life. Case law has established that:

- ▶ The principle of the sanctity of life is not absolute. Whilst Article 2 of the European Convention of Human Rights imposes a positive obligation to give LST, it does not impose an absolute obligation to provide such treatment if it would be futile and where responsible medical opinion is of the view that such treatment is not in the best interests of the patient.^{33 42 43}
- ▶ The right to life is not the same as the right to be kept alive.⁴⁴
- ▶ There is no obligation to give treatment that is futile or burdensome.³⁴
- ▶ When individuals ask for treatment which the healthcare professional has not offered and which s/he considers not clinically appropriate for the patient, the professional is not obliged to provide it. Second opinions should be arranged and/or care transferred to another healthcare professional wherever possible.^{43 45}
- ▶ Responsibility for deciding which treatments are clinically appropriate rests with the healthcare professional, who must act in accordance with a responsible body of professional opinion.⁴⁶
- ▶ LST can lawfully be withheld or withdrawn for a patient who lacks capacity in circumstances where commencing or continuing such treatment is deemed *not* to be in their best interests.⁴⁷

2.3.5 Best interests

'Best interests' are not purely confined to considerations of best medical or clinical interests, but include other medical, social, emotional and welfare factors. The court is not tied to the clinical assessment of what is in the patient's best interests and it will reach its own conclusion on the basis of careful consideration of the evidence before it, ensuring that the welfare of the child is of paramount consideration.

The court will weigh up the overall advantages and disadvantages of limiting LST, and undertake a balancing exercise to determine what the child's best interests are. In cases involving the withdrawal of treatment, the court will need to conclude 'to a high degree of probability' that it is in the best interests of the child for treatment to be withdrawn.

2.3.6 Quality of life and legal decisions

Courts have recognised that quality of life determinations should be based on the individual circumstances of the person taking account of his or her perceptions without discrimination; quality of life that could be considered intolerable to one who is able-bodied may not be intolerable to one who is born with disability or has developed long-term disability.

2.3.7 Withdrawing treatment

The courts will sanction the withdrawal of treatment in cases where continued treatment would be futile even though there is a presumption in favour of preserving life.³³

2.4 The ethical framework

No single ethical framework is likely to embrace all views on questions of withholding or withdrawing treatment but the Ethics and Law Advisory Committee of the Royal College of Paediatrics and Child Health (ELAC-RCPCH) were mindful of a number of ethical theories and principles in shaping their recommendations.

2.4.1 Fundamental considerations

The ELAC-RCPCH believes that there are three sources of ethical obligation that influence decisions about the provision of LST in children:

1. The duty of care that both healthcare professionals and parents owe to the child; in most situations these duties are fulfilled in partnership.
2. The need to respect the internationally agreed rights of the child which entail positive duties and negative constraints on actions relating to all children.
3. The requirements of UK law (see 'The legal framework').

All the above considerations overlap to some extent but all have as their focus the best interests of the child and how and by whom these may be defined.

Duty of care and the partnership of care

Moral duties and responsibility of healthcare professionals

Healthcare professionals owe special moral obligations (duties) to their patients. They must have the best interests of their patients as their paramount concern; this involves two principal duties.

The professionals' first duty is to respect life and the health of patients by preserving life, restoring health and preventing disease. They must fulfil this duty fairly, justly and to an acceptable standard. Any proposed treatment should confer maximum benefit and minimise harm, consistent with its intended purpose. Analysis of harms and benefits should include relevant emotional, psychological and social factors as well as clinical factors.

Children's healthcare professionals have an additional duty to the child's family. Part of good paediatric care involves an assessment of the harms and benefits of treatment for parents and families as a whole. Challenges may arise when the duty to benefit the child conflicts with a duty to the parents.

The professionals' second duty is to respect patients' right to make their own informed choices (autonomy). They should respect patients' rights to as much self-determination as they are capable, and respect their known or ascertainable wishes, beliefs, preferences and values. Judgements about what treatments to provide involve both facts and values. Professionals should not manipulate, coerce or deceive patients into doing what they (the professionals) believe would be in the patients' best interests.

Parents have both ethical and legal authority to make decisions on behalf of children who lack sufficient capacity to make their own informed decisions, provided that they act in the child's best interests. The parents' special relationship with their child and the value that society places on preserving family relationships gives them a unique role in evaluating which course of action will best promote the interests of the child. Normally healthcare professionals and parents act in partnership to promote the best interests of the child.

Respect for children's rights

The UNCRC (1989)²² sets out a series of 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 affirms the right of the child to the highest obtainable standards of health and to facilities for the treatment of illness and restoration of health.
- ▶ Article 13 affirms 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.

The legal duty (see 'The legal framework')

There may be occasions when there is apparent or actual conflict between ethical and legal duties and when disputes arise between the parties concerned. In this case formal legal opinion should be sought and legal intervention may be required.

2.4.2 The interests of the child

Adults are usually presumed to have the ability to determine for themselves what their own (best) interests are. Healthcare professionals should respect the choices of competent adults, whether they agree with them or not. A child's capacity to decide what their best interests are may be unknown or not developed (for example, in the case of very young children). Over time children become able to express their wishes, develop their own sets of values and gain in their ability to use information to make decisions.

Current best practice guidance actively encourages children's participation in decision making (see 'Involving children').³ If children lack capacity to make informed choices others have legal authority to do so on their behalf, provided that they act in the child's best interests.

All decisions about best interests of a child involve value judgements about what is of value in life, how best to promote the child's interests, and how different or competing interests should be weighed against each other. Different healthcare professionals and different parents may reach different answers about what would be in the best interests of the child because they have a different understanding about the relevant facts. But they may also disagree because they have different values.

2.4.3 Parental discretion, responsibilities, rights, duties and power

In the UK, as in other cultures and legal systems, parents have discretion for a wide range of decisions concerning their child, for example, education, housing, basic healthcare. Parental decisions

are generally respected in law, unless they appear to risk substantial harm to the child or are not in the child's best interests.

A family's concept of their child's best interests is likely to be determined by their own system of values. A number of influences shape a family's collective value systems; these include religious beliefs, political and cultural attitudes and life experiences. Parental values may not coincide with those of professionals. Disagreements may be aggravated by the power imbalance inherent in the healthcare professional/patient, child/parent relationship. A child's desire to make his or her own decisions may run counter to professional or parental choices. Good clinical practice at the end of life entails some way of resolving potential conflicts over what constitutes a child's best interests and who decides them (see 'Practical aspects of decision making').

Parental decision-making should be properly informed by providing the best information available and by presenting it in a form and at a pace they can comprehend. Parents whose understanding is limited by cognitive or communication difficulties should receive appropriate services to ameliorate or overcome these difficulties. An advocate, for example, from the Patient Advice and Liaison Service (PALS),⁴⁸ may help in assisting parents and child in presenting their views and wishes to the clinical team.

The central role that parents are granted in making decisions about a child's medical treatment does not mean that they will always make those decisions themselves. They may be unable or unwilling to make decisions or prefer that healthcare professionals decide on their behalf. However, the presumption should be that parents will always want to take part in discussion about limiting LST and that they should always be invited to do so. A shared model of decision making is appropriate in most circumstances.^{49 50} Where parents do express views and these are reasonable, their values should carry great weight in decision making.

2.4.4 Parental interests, wishes and professional duties

In the context of life-limiting illness it is often possible for healthcare teams, parents and children to reach agreement as to whether LST should be provided, withheld or withdrawn. In these the situations the interests of the child and family are likely to coincide.

There are two sets of circumstances when there may be actual or apparent conflict between the interests of the child and his/her parents:

1. The parents may wish for limitation of treatments that healthcare teams regard as being in the child's best interests. This situation is rare, but if it arises the parents' understanding of the relevant facts and the reason for their judgment should be explored. If the benefits of continuing treatment are sufficiently small or uncertain, the parents' views about the best interests of the child should be given serious consideration. Where the benefit to the child is clear, the presumption should be to provide treatment to the child. An independent ethical review may be helpful, but it may be necessary to refer the case to the court for an independent judgment to resolve matters.
2. The healthcare team may believe that limitation of LST is in the child's best interests, but the parents do not agree and want treatment to continue. This is the more common situation. Parental wishes and interests are important but not necessarily determinative; parents' wishes may be persuasive if the burdens to the child of further treatments are sufficiently small or uncertain.

Parental interests may overlap with the interests of the child and are difficult to separate. An approach that considers family

welfare rather than purely best interests of an individual child is a model that is used by the majority of paediatricians.^{51 52}

Nevertheless, the interests of the child should remain the primary guiding factor in treatment decisions. Referral to social care and legal intervention should be considered when there is justifiable concern that parental decisions would pose a significant risk of serious harm to the child.

2.4.5 Involving children

Although an assessment as to whether a child has legal capacity to make a decision about treatment is of the binary 'yes/no' type, appropriate involvement of children is practically important and ethically justifiable, irrespective of whether they have full capacity to make decisions for themselves. It is consistent with a rights respecting, non-discriminatory approach.

Children's capacity to make decisions evolves over time and at different rates that broadly accord with their cognitive ability, developmental level and experience. Thus children who have had extensive experience of disease and its treatment, for example, repeated cycles of chemotherapy, organ transplantation, will have more informed views about continuing treatment than an adult facing such treatment for the first time. Equally, young children may have no experience of decision making and their value systems remain unformed.

There are many ways of engaging children and involving them in decision making. These include (a) talking *with* them, (b) listening to them and responding to their concerns, (c) using appropriate techniques, for example, play to increase understanding and (d) acting in a way that demonstrates that account of their views has been taken.

The ELAC-RCPCH believes that there should be a presumption that children will be involved in decisions about treatment (including those concerned with limitation of LST) wherever possible and at a level that reflects their ability, understanding and experience. Healthcare professionals should enhance a child's understanding and capacity by appropriate techniques.

Some children may have no views about proposed care (for example, because of immaturity, or when illness, injury or disability limit their understanding). Others may prefer that healthcare professionals or parents decide for them, although this apparent preference should be checked and not assumed.

In the case of children who have extensive experience of illness and medical treatment it will often be reasonable to presume a greater degree of competence in decision making, but assessment of competence should nonetheless be undertaken.⁵³

2.4.6 Children with disabilities

One of the most challenging and difficult areas involves the question of limiting LST for infants and children with severe disabilities.¹⁵

According to the World Health Organization, 'disabilities' is an umbrella term that covers impairments, activity limitations and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action, while a participation restriction is a problem experienced by an individual in involvement in life situations.⁵⁴

In UK Law a person with disability is defined as someone who has a physical or mental impairment that has a substantial and long term adverse effect on their ability to carry out normal day to day activities.²⁵ The Equality Act protects people with disabilities from unfair direct and indirect discrimination and from victimisation and harassment.

Disability is a complex phenomenon, reflecting an interaction between features of a person's body and the society in which he or she lives. Disabilities may vary qualitatively (they may affect movement, cognition or sensory functions), or quantitatively, depending on their degree; there are different contributors to disability. Integration of the medical and social models of disability has been an important consideration in meeting the needs of disabled children and their families. The impact of a disability on a child's life is determined by the nature of their underlying impairment and by the resources available to support them. Although healthcare professionals may focus on the medical elements of disability (the medical model), the availability—or otherwise—of social supports for an individual and their family may be of equal or greater importance in determining how much they are able to enjoy and participate in life. Individuals with disabilities can enjoy lives of high quality, and take part in a wide range of activities. It is important that the value individuals with disabilities and their families place on their lives are recognised by healthcare professionals, especially in acute medical situations where children and families are far removed from their normal environments and unable to function at their usual level.

Healthcare professionals should, whatever the clinical circumstances, ensure that the language that they use to describe or discuss disabilities is neutral, accurate and appropriate. They should avoid preconceived notions of what disabled children look, sound or behave like and avoid following negative stereotypes of the lives of those with disabilities. They should not unwittingly contribute to avoidable raised premature death rates associated with disability.

Quality of life and disability

The relevant factors in assessing quality of life for children with disability in relation to decisions about LST do not differ from those applied to those without disability; they should include: the nature of future life for that individual, the value that they will derive from it and the relative balance of positives and negatives for them. It is not a comparative judgement about the quality of life of different individuals, nor is it a determination that some individuals are of higher value or worth than others. However, as with non-disabled children there should be due consideration of the impact of treatments on the child's ability to communicate, experience awareness of those around them, experience pleasure, attain goals and be independent, and the negative impact of treatment in terms of pain, discomfort and distress.

If a child is predicted to have an impairment in their quality of life as a result of treatment, a primary consideration is whether and how their experience of life may be improved. The provision of appropriate supports can make a significant difference to the experience and quality of life of children and adults with impairment. There is an ethical and legal obligation to provide high-quality care to those with impairment, so as to maximise their quality of life, insofar as this is possible.

The ELAC-RCPC 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 them⁵⁵ and that decisions to limit LST in children with disabilities should be made on the same basis as in non-disabled children.

2.4.7 Transition to adult services

Increasingly children with life-limiting illnesses will live beyond their 16th or 18th birthdays. Arrangements for transition should accord with best practice, subject to audit and respectful—insofar as possible—of the wishes, preferences, beliefs and values of those concerned. Arrangements should accord with

professional guidance and be subject to age-appropriate and/or age-determined legislation, for example, Mental Capacity Act,²⁴ Equality Act.²⁵ Limitation of treatment decisions or arrangements for end of life should be in accordance with age-related ethical, legal and professional guidance and statute law insofar as they differ for this age group (see for example, GMC 'Treatment and care towards the end of life: good practice in decision making',² Good medical practice).³

2.4.8 Axioms on which to base best practice

From these fundamental ethical and legal considerations flow a number of general axioms, which may govern practice. These are:

A. In relation to decision making

1. Optimal ethical decision making requires: open and timely communication between members of the healthcare team and the child and family; respecting the values and beliefs of those involved; and the application of fundamental ethical principles, including respect for human rights.
2. Decisions between treatment options, including those of limitation, withholding or withdrawing treatment, should be freely made by those with the capacity or legal authority to do so, on the basis of sufficient information. In circumstances where it is not possible or feasible to undertake this process, clinically appropriate treatment should be provided unless there are sufficient grounds to believe that it will be unsuccessful or will produce significant burdens for the child.
3. Resolution of disagreement should normally be achieved by discussion, consultation and consensus.
4. Parents have ethical and legal authority to decide on behalf of children who are unable, for whatever reason, to express preferences, unless they are clearly acting against the child's best interests. If they are unable, unwilling or persistently unavailable to make decisions on behalf of their child, the court's intervention should be sought.
5. The wishes of a child who has obtained sufficient understanding, maturity and experience in the evaluation of treatment options should be given substantial consideration in the decision-making process.
6. The antecedent wishes and preferences of the child, if known, should also carry considerable weight, provided that conditions at the time for action match those envisaged in advance.
7. Legal intervention should be considered when disputes between the healthcare team, child, parents and carers cannot be resolved by appropriate attempts to achieve consensus, for example, clinical ethics consultation, use of advocacy and liaison services, intercession by religious leaders and mediation.

B. In relation to circumstances in which treatment might be withheld or withdrawn

1. There is no significant ethical difference between withholding, limiting or withdrawing (stopping) treatments, given the same ethical objective.
2. The professional duty to preserve life is not an absolute one that applies at all costs. Treatments should only be provided where they are in the child's best interests.
3. It is ethical to withhold or withdraw LST if:
 - a. such treatment would be medically inappropriate and could not achieve its intended purpose of preserving life or restoring health
 - b. treatment would no longer be in the best interests of the child in that its burdens outweigh the benefits
 - c. a competent child refuses to consent to the starting of treatment or requests that it be discontinued

4. A redirection of management from LST to palliation represents a change in aims and objectives of treatment and does not constitute a withdrawal of care. Although medical treatment that has no overall benefit may be ethically withdrawn, appropriate and effective palliative care should continue to be provided.
5. It is ethically appropriate to withhold or withdraw LST (subject to the above conditions) and to provide appropriate palliative treatments (including analgesia and sedation), even if it is reasonably foreseeable that the latter may hasten death. These steps are a desirable and acceptable part of contemporary end-of-life care and do not constitute euthanasia.
6. It is not permissible for healthcare professionals to take active steps that are intended to end the life of a child.

3. THE PROCESS OF DECISION MAKING

3.1 Practical considerations; substantial issues in decision making

3.1.1 To withhold, to withdraw or to limit?

Withholding, withdrawing and limiting life-sustaining treatments are regarded as being *ethically* equivalent. Ethical analysis and professional guidance, published since the original RCPCCH framework document, have supported this view.^{2 18}

In the UK withholding and withdrawing treatment are also regarded as *legally* equivalent.⁴⁶

The major legal consideration in decision making is whether or not the proposed or actual treatment would be in the best interests of the patient, whether adult or child.

This means practically that it is permissible to withdraw a treatment a patient is receiving if it would have been permissible to withhold the same treatment (if it were not already being given) and vice versa.

Surveys of medical and nursing staff in the UK and internationally, suggest that only a minority (21–54%) believe in the ethical and legal equivalence of withdrawing and withholding treatment. Many prefer to withhold rather than withdraw LST, and regard a decision not to start treatment as an omission to act and morally preferable to an action to withdraw.

However, even if healthcare professionals find withdrawing treatment more psychologically and emotionally challenging than withholding treatment, this should not influence treatment decisions or their practical implementation.

3.1.2 Dealing with uncertainty

It is rarely possible to have complete certainty about outcome when making any clinical decision, nor is this normally regarded as necessary. However, the gravity of the consequences of decisions to limit LST will usually demand a relatively high degree of confidence regarding outcomes.

In acute situations it is usually necessary to give LST first and to review the decision to continue when enough information is available, taking into account more experienced clinical opinion, the evolution of the clinical state, or the results of investigations. Neonates should almost always be resuscitated in the labour ward, unless there is a clear decision to do otherwise made with the consent of parents and based on appropriate guidelines.^{15 56}

Such situations are most likely to arise in the care of neonates, including those below the limits of viability, those in whom there is the presence of severe life-limiting conditions and/or congenital anomalies and those with poor response to resuscitation.

In less acute situations it may still be possible to attain higher levels of certainty by continuing to provide LST whilst waiting for more information to be assembled. This should be balanced

against the impact to the child of ongoing treatment and the suffering that might ensue. Decisions should not generally be rushed but there may be some circumstances in which urgent decisions are necessary so as to avoid a child's suffering being prolonged.

In critical care areas, for example, emergency departments, labour wards and intensive care units, there should be frequent review of all decisions including those related to the provision of LST. There should be a willingness to respond to changing clinical circumstances.

Treatment should be based on the most up-to-date clinical evidence and/or appropriate guidelines insofar as these exist. If there is a need to obtain more information to guide decision making, this should be clearly explained to the parents and child if competent. A realistic time frame for assembling information should be given.

The need for monitoring response to treatment and the means whereby this will be achieved should be explained. The basis for considering whether treatment should be continued or withdrawn should be made clear, for example, if treatment proves too burdensome or does not achieve its intended benefits.

3.1.3 Situations in which it is appropriate to limit treatment

The underlying ethical justification for all decisions to withhold or withdraw LST is that such treatment is not in the child's best interests. There are three sets of circumstances where it may be appropriate to consider limitation of treatment.

Limited quantity of life

If treatment is unable or unlikely to prolong life significantly, it may not be in the child's best interests to provide it.

A. Brain death

Death occurs when a child has irreversibly lost their capacity for consciousness and their capacity to breathe and maintain their cardiovascular circulation.

A determination of death should be made in accordance with accepted medical standards as set out in the code of practice of the Academy of Medical Royal Colleges.⁵⁷

Death may be diagnosed following cardio respiratory arrest or, in a comatose child, it may be diagnosed following evidence of irreversible cessation of brain stem function. When death is diagnosed following formal confirmation of brain stem death by agreed medical criteria, intensive technological support is no longer appropriate and should be withdrawn, unless organ donation is being considered.

B. Imminent death

Here, despite treatment, the child is physiologically deteriorating. Continuing treatment may delay death but can no longer restore life or health. It is therefore no longer appropriate to provide LST because it is futile and burdensome to do so.

Children in these circumstances would be likely to derive little or no benefit from CPR. The aim should be to provide emotional and psychological support to the child and family and to provide them with privacy and dignity for that last period of the child's life (see 'Palliative care' on palliative care).

C. Inevitable demise

In some situations death is not imminent (within minutes or hours) but will occur within a matter of days or weeks. It may be possible to extend life by treatment but this may provide little or no overall benefit for the child. In this case, a shift in focus of care from life prolongation per se to palliation is appropriate.

In both 'Imminent death and Inevitable demise' (above) the early provision of sensitive palliative care is ethically justified and in accordance with principles of good medical practice (see 'Palliative care').

Limited quality of life: where there is no overall qualitative benefit

Considering quality rather than quantity of life is more problematic because of potential or actual differences in views of the healthcare team and children and families as to what constitutes quality of life and the values that should be applied to define it.

In some children, continuing treatment may prolong life significantly. Yet it may be in their best interests to consider limiting it if there is no overall benefit in prolonging life because of the adverse impact entailed. In entering discussions about treatment limitation it is important to acknowledge the importance of the value that the child and his/her parents place upon their life and their view of its quality for that child, regardless of disability. These discussions may arise in the context of the burdens imposed by a child's illness and/or the treatments that the child is already receiving or that are proposed, their inability to benefit from treatments, or a combination of all three.

A. Burdens of treatments

Some forms of medical treatments in themselves cause pain and distress, which may be physical, psychological and emotional. If a child's life can only be sustained at the cost of significant pain and distress it may not be in their best interests to receive such treatments, for example, use of invasive ventilation in severe irreversible neuromuscular disease.

It is important that all options to relieve or overcome the negative effects of treatment are explored before proposing that it should be limited. However if such treatment can only be delivered at the expense of compromising the child's consciousness, for example, by deep sedation, its potential benefit may be significantly reduced. Other examples of particularly high-impact treatments include ECMO, renal dialysis and, sometimes, intensive chemotherapy.

B. Burdens of illness and/or underlying condition

Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome the potential or actual overall benefits in sustaining life. Some children have such severe degrees of illness associated with pain, discomfort and distress that life is judged by them (or on their behalf if they are unable to express their wishes and views) to be intolerable. All appropriate measures to treat and relieve the child's pain and distress should be taken. If, despite these measures, it is genuinely believed that there is no overall benefit in continued life, further LST should not be provided, for example, in advanced treatment-resistant malignancy, severe epidermolysis bullosa.

C. Lack of ability to derive benefit

In other children the nature and severity of the child's underlying condition may make it difficult or impossible for them to enjoy the benefits that continued life brings. Examples include children in Persistent Vegetative State (PVS),¹ Minimally

Conscious State, or those with such severe cognitive impairment that they lack demonstrable or recorded awareness of themselves or their surroundings and have no meaningful interaction with them, as determined by rigorous and prolonged observations. Even in the absence of demonstrable pain or suffering, continuation of LST may not be in their best interests because it cannot provide overall benefit to them. Individuals and families may differ in their perception of benefit to the child and some may view even severely limited awareness in a child as sufficient grounds to continue LST. It is important, here as elsewhere, that due account of parental views wishes and preferences is taken and due regard given to the acute clinical situation in the context of the child's overall situation.

Although it is possible to distinguish these different groups of decisions to limit LSTs that are based on quality-of-life considerations, in practice combinations may be present. For example, a child or infant in intensive care may have sustained such significant brain injury that future life may provide little benefit, while both intensive treatment and future life are likely to cause the child substantial pain and distress.

Informed, competent, supported refusal of treatment

Adults who have the capacity to make their own decisions have the right to refuse treatments (including those intended to sustain life), even if professionals regard such treatments as being in the adults' best interests.

In some circumstances the child or young person, who often has extensive experience of illness, clearly and repeatedly refuses treatment that professionals may regard as being in their best interests. In practice these refusals are likely to occur in situations where the young person's life is limited in quantity or quality or both (as outlined in 'Limited quantity of life and Limited quality of life: where there is no overall qualitative benefit') and where limitation of treatment may have already been considered as a possible option. Examples might include a child who requires cardiac transplantation for cardiomyopathy induced by therapy for leukaemia, or lung transplantation for complications of cystic fibrosis.

These circumstances should trigger a careful and detailed assessment of the child's/young person's understanding of their illness, their capacity to make such far-reaching decisions and their understanding of the impact of their decision on their family. There should also be a thorough exploration of parental/family views on treatment options, including provision of supportive care and determination of whether a consensus exists or can be reached (see 'Practical aspects of decision making').

If the child/young person does understand the nature and consequences of their decision, is assessed as having capacity to make the decision and is supported by their parents, the provision of further LST may no longer be ethically justifiable even if it has the potential to provide some limited clinical benefit.

3.1.4 Spectrum of decisions and parental discretion

In cases where treatment limitation is considered, judgements of the balance of benefits and burdens may differ between parents and the healthcare team (see 'Parental interests, wishes and professional duties'). For example, some parents may wish that an older child is not informed of their condition when the child themselves may have clear insight into its nature and the healthcare team believe that they should disclose it.

Benefits may be so far outweighed by burdens that it would not be ethically or morally appropriate to provide treatment even if parents request it. This applies when the child is brain

¹PVS- 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.

dead, or where quality of life is seriously compromised by burdens of illness or treatment (see 'Practical considerations; substantial issues in decision making' above). In these situations treatment is judged to be medically inappropriate (sometimes also called 'futile'), and there is no ethical (or legal) obligation to provide it.

Alternatively, benefits and burdens may be more finely balanced. Assessing whether continued treatment is in the interests of the child can be extremely difficult. There may be legitimate differences between individual families in their judgements about the benefits of treatment and of continued life. Where parents have an understanding about the likely benefits of treatment and the interests of the child, their views should be given considerable weight in the decision-making process (see 'Parental interests, wishes and professional duties'). This means that there may be circumstances in which some children with very similar conditions and prognoses are assessed as benefiting from continued LST whilst in other cases the assessment may be to have such treatment withdrawn.

In contrast, it may be that the overall benefits of treatment are so great that the assessment is that LST should continue to be provided, even if parents disagree with that assessment. It is uncommon for parents to oppose LST in this situation, but if they continue to refuse to consent, legal action should be taken to safeguard the interests of the child until a formal determination of the child's best interests can occur.

3.2 Practical aspects of end-of-life care: responsibilities, treatments that may be limited, appropriate or permissible actions

3.2.1 Clinical responsibilities of the healthcare team

Healthcare teams have individual and collective obligations to act in the child's best interests. The healthcare team must always introduce treatments for the overall benefit of the child, and should consider withdrawing them when they are no longer of benefit. All remediable causes for the child's condition must be excluded, for example, drugs, metabolic encephalopathy.

Because outcomes at the start of treatment may be uncertain, the team should wait until enough information (not feelings) about the child's clinical condition and other relevant matters is available (see 'Dealing with uncertainty'). This delay may become a source of tension for all. Information should be collected with the aim of providing a clear diagnosis and an indication of the likely prognosis. Ultimately, decisions to withhold or withdraw certain treatments will be based on probabilities rather than certainties. Sometimes children, in whom LST is withheld or withdrawn, may survive.^{58–63} In these circumstances continuing support and palliative care should be provided. In situations where treatment is withheld or withdrawn, the healthcare team needs to be flexible in the face of changing circumstances, as the primary intention of limiting treatment is not the death of the child.

3.2.2 The range of treatments that may be withdrawn

There are many different types and intensities of treatment that it may be appropriate to consider limiting, depending on the severity of the illness or the situation. These may include experimental treatments (ie, those currently not validated by research evidence), CPR, mechanical ventilation, intravenous inotropic agents, antibiotics, CANH and ECMO.

The appropriateness of continuing or withdrawing any particular treatment depends on both the indication for that treatment and on the justification for limiting LST ('Practical

considerations; substantial issues in decision making'). Where the reason for withholding or withdrawing LST is on the basis of the burdens of treatment or inevitability of demise, it may be appropriate to limit some LSTs but not others. For example, it may be appropriate to withhold invasive ventilation in a child with a severe neuromuscular disorder, but to provide other less burdensome treatments, including non-invasive respiratory support, nutritional support, antibiotics, or blood transfusions. In other situations, where the probability of recovery is very low, it may be appropriate to withhold CPR, but to provide other forms of LST, including mechanical ventilation for acute respiratory failure.

These matters, amongst other subjects relating to determination of best interests, should if possible be addressed before acute situations arise. It is particularly important to discuss these matters in the context of chronic life limiting or life shortening conditions, before acute episodes occur or they become life threatening conditions. Forward planning enables the topic of adverse outcomes to be discussed in a sensitive manner and enables the views of the child and family to be ascertained and appropriate care plans to be developed. Such a process facilitates the implementation and communication of professional guidance. Whilst the role of paediatric advance care plans in the UK awaits formal evaluation,⁶⁴ any decision to limit treatment must remain consistent with the contemporary legislation of the relevant jurisdiction for example the relevant Children Act or an Education Health and Care (EHC) plan agreed under the Children and Families Act 2014.

It is important to be clear to all involved (including the child when competent and where appropriate) as to which treatments are appropriate and which are not, which will be provided, and which will not. The range of chosen interventions is increasingly defined by end-of-life care plans, acute emergency care plans or Limitation of Treatment Agreements (LOTAs) or personal resuscitation plans⁶⁵ rather than Do Not Attempt CPR (DNA CPR) Orders. Because parents may change their minds over the details of care plans or treatment agreements the precise details of both need to be re-confirmed.

Where the justification for limiting treatment is because of the likelihood of imminent demise or the burdens of the child's condition or limited ability to derive benefit (see previous 'Practical considerations; substantial issues in decision making'), it may be appropriate to withdraw or withhold all treatments except those aimed at keeping the child comfortable. The general and specific measures necessary for this can form part of limitation of treatment agreements or end-of-life care plans.

3.2.3 Cardiopulmonary resuscitation

The purpose of CPR is to attempt to restart the heart or breathing and restore circulation after a cardio-respiratory arrest. It often includes invasive procedures, for example, obtaining access to the child's airway and circulation. Its success rate is dependent on circumstance but generally lower than is commonly perceived by the general public. Both CPR, and the physiological process leading up to cardio-respiratory arrest, may have both harmful side effects and adverse consequences, for example, hypoxic brain damage and poor neurological outcomes. If it is unsuccessful it may mean that death occurs in a traumatic and undignified manner and often in the absence of parents.

A number of professional bodies in the UK have published advice for healthcare professionals on when to attempt resuscitation and when it is inappropriate to do so.^{66 67}

In essence, an attempt to provide CPR is inappropriate if:

- ▶ It is unlikely to be successful in restarting the heart or breathing because of the child's underlying condition.
- ▶ There is a limitation of treatment agreement or other end-of-life care plan that excludes its use.
- ▶ Even if successful it is likely to produce more burdens than benefits.
- ▶ In practice these are the same conditions that apply to withholding or withdrawing other forms of treatment as set out in 'Practical considerations; substantial issues in decision making'.

Guidance for parents and carers on resuscitation and its likely burdens, risks and outcomes is also available.^{68 69} Nevertheless, some parents may request that their child receives CPR despite a small chance of success or high risk of adverse outcomes. Parental understanding about CPR and outcomes and the reasons for their request should be explored; it may be possible to reach agreement on the extent to which treatment should be limited. If this is not practicable the possible options for the parents, including second opinions and legal review, should be discussed. However, clinicians cannot be compelled to provide treatment they feel not in the child's best interests.

DNA CPR decisions apply only to CPR and it does not follow that other treatments will be withheld or withdrawn. Other treatments and care should continue to be provided if it is clinically appropriate and in the child's best interests to do so. Some hospitals have moved away from such binary negative type 'orders' to focus on more positive aspects of care which might appropriately be provided for children in these difficult circumstances, in the form of end-of-life care plans or pathways or advanced care plans.

DNA CPR orders do not override clinical judgement or discretion. For example, they may not be followed if a child suffers a cardiac or respiratory arrest from a reversible cause, for example, acute aspiration or one not envisaged when the original order was made.

3.2.4 Clinically assisted nutrition and hydration

All children have a basic need for food and drink to maintain adequate levels of nutrition and hydration and to prevent the adverse outcomes associated with malnutrition or dehydration. This applies equally to those with life-limiting illness.¹⁷

Giving food by mouth is part of basic care and should be provided for those who can tolerate it without serious risk, for example, choking, aspiration, and who appear hungry and thirsty.⁷⁰

Separate assessment of a child's fluid and nutrition needs should take place alongside assessment of their clinical condition and forms a basic part of care. It will determine whether clinically assisted provision of nutrition and hydration is required. CANH is appropriate in many children, including those with severe impairment or terminal illnesses.

CANH may be provided by naso-gastric or naso-jejunal tube or by Percutaneous Endoscopic Gastrostomy (PEG) or in some cases by the intravenous route. Hydration may be provided subcutaneously as well as by the above routes.¹⁷

CANH is legally regarded as a medical treatment and one that sustains or prolongs life.⁴⁷ It may be used for symptom relief and may increase quality of life, but it also carries risks. There may be concerns that withdrawal of CANH in semi-conscious or unconscious children may unwittingly increase their suffering. On the other hand, attempts to provide CANH when its intended benefits cannot be achieved may also fail to promote the interests of the child.

The role and purpose of CANH should be considered very carefully. Decisions as to whether CANH should be provided should be based on whether it provides overall benefit to the child and should be discussed fully with the family.

CANH should normally be provided for competent children who request it in order to sustain life, but its consideration will be dependent on the circumstances of the individual child. Its introduction may be entirely appropriate, for example, in a child with a swallowing disorder due to a slowly progressive neurodegenerative disease, but rarely for a child with rapidly progressive, disseminated malignant disease.

Because CANH is a LST it may be withheld or withdrawn in the same circumstances and for the same reasons as other forms of LST. It would therefore not be appropriate to provide CANH in children who face imminent demise, where its addition would prolong or increase the morbidity of the dying process, or in those circumstances where its lack of overall benefit to the child warrant an exclusively palliative approach. Although withholding or withdrawing CANH may be morally permissible, it is not obligatory. There was until recently (2014) no specific statute or case law that governs the provision of CANH in children with life-limiting illness, although there may be no legal obligation to provide it in those who are dying.³⁴ It nonetheless seems necessary to seek formal legal advice in these circumstances.

For these reasons it may be ethically appropriate to consider withholding or withdrawing CANH in children in PVS or Minimally Conscious State. However, UK courts have indicated that for PVS cases at least an application to withdraw CANH must be made to them. Paediatricians in these circumstances should obtain legal advice as to how to proceed.

Parents should be fully involved in the decision making and should support the decision to withhold or withdrew CANH. It is important that comprehensive palliative care measures for the child, including appropriate sedation and oral hygiene, are in place.

3.2.5 Muscle relaxants and end-of-life care

Drugs that produce muscle relaxations (MRs) are widely used in adult, paediatric and neonatal intensive care to facilitate mechanical ventilation. MRs on their own do not provide sedation, anxiolysis or analgesia.

MRs have been used after withdrawal of mechanical ventilation to treat or prevent terminal gasping, a common symptom in dying patients. Terminal gasping consists of deep, irregular inspiratory efforts that are probably a physiological response to hypoxia. It is distressing for parents and staff to witness and may lead to requests that treatment is given to suppress it. However, the use of MRs in this setting is problematic; if terminal gasping is associated with distress MRs will mask the symptoms of respiratory distress without treating it. They will also lead to lack of respiratory effort and rapid death, and their use may be interpreted as an intention by medical staff to hasten death.

The ELAC-RCPCH considers that there is no justification for the prescription of MRs immediately prior to, or following, withdrawal of mechanical ventilation in order to prevent terminal gasping or to hasten death. A full explanation of the symptom of terminal gasping and its causation should be given to parents and staff together with appropriate palliative care to prevent distress and suffering.

3.2.6 Palliative care

Palliative care is intended to alleviate the harms produced by illness and disabilities and is consistent with the moral duties of medicine. Good palliative care maximises a child's potential to sustain their capabilities. It fulfils the duty to respect and

promote such autonomy as the child is capable of, as well as providing support for parents and carers. Palliation aims at symptom relief irrespective and independently of any intention to provide curative or life-sustaining treatment. Parents and, where possible and appropriate, children should be given a clear explanation of the nature and purpose of palliative care, especially if there is parental scepticism about its use or reluctance to consider it. To the extent that palliative care is able to produce benefits and reduce harms, its use from early on in life-limiting illness is desirable.

Palliative care services may therefore be introduced alongside potentially curative or life-prolonging treatments, or may be the main focus of care.⁷¹ The ELAC-RCPCCH believes that a re-direction of management from LST to palliation represents a change in aims and objectives of treatments and does not constitute a withdrawal of care.

There is a strong moral duty to provide palliative care to children with life-threatening and life-limiting illnesses, whether delivered by a specialist palliative care team or as part of the overall care delivered by the clinical team already caring for the child. Palliative care support may begin whenever it becomes apparent that the child's illness may result in premature death. It should entail consideration of the child's physical needs, for example, pain and symptom relief 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. The introduction of palliative care should not be left until a decision is made to withdraw or withhold life-sustaining treatment. In making such momentous decisions, families need as much information about the palliative care support available, and their options, as they do about the role of active interventions. Without this information, they cannot make an adequately informed decision to pursue or withhold/withdraw active interventions. Therefore, it is often helpful to involve a palliative care specialist early in the course of discussions with the family.

A palliative care team, wherever based, will be able to support the family and to plan for the child's future, however short that may be. Many teams are able to offer support for continued care in a family's preferred location. This may include transferring a child out of hospital for ventilation withdrawal in a preferred place of care/place of death.

Careful planning and communication is needed to ensure continuity of care for the child and family, particularly when they are moving between hospital and home. A key worker (often the paediatric community nurse or a palliative care specialist from the local community, hospice or hospital) is essential to coordinate this, especially where it is anticipated that palliative care may be needed for an extended period of time and involve a number of healthcare professionals. A dedicated palliative care team will be able to provide bereavement support for the family before and after death. It is likely that this support can be provided in the family's own community and for however long they need. A palliative care team can support the child and family to live in the knowledge of an uncertain future. They can provide practical and emotional support for day-to-day care and support for symptom management. They will work alongside other medical and nursing teams involved in the child's care to support changing goals of care and advanced care planning.

Including palliative care support early in the course of a child's illness will ensure that, whatever the outcome, the child and family have access to appropriate care and support, wherever and whenever it is needed. Palliative care should not be reserved only for those children who are actively dying.

3.2.7 Organ donation

Organ donation should be considered in any child dying in the intensive care environment. Discussions about organ donation must be separated from discussions about withholding or withdrawing LST.⁷² Only after a decision has been made to withhold or withdraw LST is it appropriate to raise with the family the possibility of organ donation after death.^{72 73} This would normally be the function of the Specialist Nurse in Organ Donation.

Donation may only proceed after certification of death. In some cases certification will follow confirmation of brain stem death by formal brain stem testing using recognised protocols.⁵⁷ In children who die following withdrawal or withholding of LST, death is confirmed and certified using standard cardio-respiratory criteria. If organ donation follows, it is referred to as Donation after Circulatory Death. Donated organs are removed at a standardised predetermined short interval after death so as to minimise the warm ischaemic time for the donated organs.

Discussing the possibility of organ donation with the parents of a child who is approaching death requires skill, sensitivity and tact. In the case of older children it is important to ascertain any previously expressed views. The independence of organ donation from clinical care should be established at the outset of any discussion.^{74 75}

In cases where it is appropriate to do so, nationally agreed procedures and guidelines for the identification of potential donors and the notification of Specialist Nurses in Organ Donation should be followed. The appropriate legal requirements and their supporting codes of practice must be observed in discussions with the parents.^{76 77} In particular, it should be emphasised that the responsibility for deciding whether the child would be a suitable donor rests with the transplant team and not with the treating team.

3.3 Practical aspects of decision making

3.3.1 The basis of decision making by teams

Whether or not an intervention is of benefit is a value judgement based on prediction of outcomes. Deciding what outcomes or treatments are intolerable or unbearable, or what risks are acceptable, is an intrinsic part of the decision-making process. This is not confined to clinical considerations alone and contextual factors relevant to the circumstances of the child and their family should be taken into account.

All members of the treating healthcare team need to be part of the decision-making process; their individual views should be sought and accorded due weight. The latter will depend on the knowledge, understanding and experience (both clinical and moral) that those individuals possess. Greater openness between disciplines and grades will enhance mutual understanding of individual roles and responsibilities and heighten the sense of shared moral responsibility. The fact that some members of the team may have difficulties in 'letting go' should be acknowledged and addressed.

Decisions should be made in partnership with the parents on the basis of shared knowledge and mutual trust and respect. The perceptions that parents and children may have of their roles and responsibilities in decision making should be acknowledged. Clinical teams need to discover the extent to which parents and children wish to assume responsibility for decision making and work within those parameters. This approach should maximise participation with which all participants feel comfortable and is likely to enable individuals to live with the decisions they make.

Ultimately, the members of the clinical team carry the shared moral responsibility for decision making, as part of their moral and legal duties as healthcare professionals. Teams can develop moral responsibility by reasoning together.

3.3.2 Obtaining second opinions

Obtaining an independent second opinion from another clinician who has experience of the child's condition may be helpful. It is essential when the team have limited experience in managing the child's condition, or there are uncertainties about specific items of symptom management, or where risks and burdens of a particular treatment are unclear. Many major medical decisions require a factual second opinion for legal reasons as well as clinical assurance, for example, termination of pregnancy, brain stem death.

Paediatricians may also seek second opinions from colleagues to enable parents and children to come to terms with diagnosis and prognosis and to provide themselves with reassurance that their assessments are appropriate.

Obtaining a second opinion as to the advisability of withholding or withdrawing LST will involve value judgements. Seeking a second opinion is not a legal requirement. It does conform to principles of good ethical decision making and the due process that good clinical governance requires. Those providing second opinions should receive clear instructions as to what is expected of them and the specific questions they need to address.

3.3.3 Resource considerations

The primary consideration in decisions about limiting LST is whether or not treatment is in the child's overall best interests. However, decisions about treatment options may be complicated by resource constraints, for example, funding restrictions on certain treatments or lack of availability of facilities, for example, intensive therapy unit (ITU) beds and staff. Parents sometimes express the concern that doctors are influenced by a lack of available resources in their judgement about the appropriateness of treatment.

Previous legal decisions have focussed on the child's best interests, rather than how resources should be used. Courts have acknowledged that healthcare resources are limited but have generally declined to comment on how those resources should be allocated.

Questions of what treatments are in the child's clinical best interests must be separated from questions of available resources. Costs are an irrelevant consideration if a particular treatment clearly cannot provide overall benefit and is not in the child's best interests. Resource implications of providing treatment may be relevant in cases where the overall clinical benefit to the child is open to debate and where provision of the treatment may pose significant risks of harm to the child.

Healthcare teams may therefore not be justified in providing treatments that are highly expensive or limited in availability and that appear to offer little benefit to the child. Ideally, these decisions to limit treatment should be based on clear and consistently applied policies developed at the institutional, local or community level.⁷⁸ Any decisions to prioritise patients and treatments should be fair and based on the patient's ability to benefit and should avoid discrimination, for example, race, age, gender, social status.⁷⁹

Before declining parental requests for treatments, second medical opinions and ethics consultation may be helpful. Parents should, where possible, be given an opportunity to find an alternative provider who is willing and able to provide treatment.

The decision-making process should be open, honest and accountable; it should avoid factors that could introduce discriminatory access to healthcare. The ethical criteria for decision making should be clearly explained to all concerned.

The ELAC-RCPCH do not believe that decisions about who is offered intensive care should be motivated by resource constraints, but should be determined by whether such care was appropriate for that particular child at that time. However, this might be changed in exceptional circumstances, for example, Pandemic Influenza, although actions at this time would still need to be in accordance with an agreed moral framework.

3.3.4 Communication as part of decision making

Within the healthcare team

When the question of withholding or withdrawing treatment is raised, all members of the clinical team should have an appropriate opportunity to express their views and opinions. For those who feel hesitant or afraid to voice their opinion, 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 is 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 withhold or withdraw treatment in every case. The consultant in charge of the case should lead the decision-making process and should always bear the final responsibility for the chosen course of action. Team discussions about the patient are a necessary learning experience for all concerned. Senior members should facilitate this by sharing and interpreting information from previous similar experiences, but should also consider new perspectives and interpretations fairly.

Decisions to withhold or withdraw LST should be clearly understood and documented in the child's notes by the clinical team.

With the family

When the option of withdrawal of LST has been raised, 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.⁸⁰ The child, as far as he or she is able, their wider family (for example, siblings) and any other individual (for example, religious advisor or friend) whom the parents or child nominate, should also be involved. The parents (and child if appropriate) should be provided with adequate information and adequate time to understand and assess it, with time also to obtain alternate advice if they so wish (see also 'Obtaining second opinions') and if circumstances permit. Siblings can also have important insights into the feelings of their sick brother or sister. The final decision should be made with the consent of the parents, though the clinical team must take the main responsibility for the decision. This can help to alleviate the burden of guilt that some parents feel.

A full formal record of all communications with the family should be kept. This should include advance care plans and personal resuscitation plans. DNA CPR Orders and decisions to withhold, withdraw or limit LST must be clearly recorded in the child's clinical notes. A written account of the process and of the factors leading to this decision should also be recorded.

If death ensues, 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 examination, if one has been performed.

No matter how careful the diagnoses during life, the ELAC-RCPCB believe that a sensitive request for a post-mortem is usually appropriate. Information from the post-mortem examination will help to consolidate and confirm diagnoses made during life and will also help to provide certainty for the parents and the clinical team. Detailed information on the processes involved are available and should be explained to parents.⁸¹ The results of the post-mortem should be given to parents as soon as possible and a written copy of the findings provided 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.

Communication with primary healthcare and community services

When a decision is being made about withholding or withdrawing LST, it will usually be appropriate to include the primary healthcare 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 outcomes—especially 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. This requires careful communication and coordination of practical arrangements between all parties involved, for example, hospital clinical team, primary healthcare team, community paediatric nursing services and local palliative care units. Local protocols policies and procedures should be followed and so that all involved are clear about roles, responsibilities and process. 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-h access to paediatric care and advice. Local teams will need 24-h access to advice and expertise in symptom management in palliative care.

3.3.5 Resolution of different opinions

Members of healthcare teams may have religious, moral or personal beliefs that produce significant conflicts over withholding or withdrawing LST within the team. For example, they may feel that they are unable to comply with decisions to withdraw CANH, even though it is felt to be in the child's best interests to do so. Conflicts of a similar nature may also arise between healthcare teams and families, and between family members. The latter may be especially problematic if there has been family break up or where parents have very different values and opinions over what should be done. Where these seriously impact on the child's care they should be sensitively explored and time and resources made available to try to resolve them (see 'Support from external agencies')

Where there is a lack of agreement within the team, between different teams or between the team and the family it is important to analyse its origins. Where disagreement stems from different understandings of the issues, more time to consider them and better communication may resolve the tension. Where there is anxiety about the degree of certainty concerning the medical facts, the need for further investigations that might help to resolve this should be considered. 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 healthcare team is not essential (see 'The basis of decision making by teams'). Those who do wish to mount a conscientious objection to a decision should ensure that their duties are covered.

Resolving a difference of opinion between the team and the family may occasionally require additional input from other agencies—see 'Support from external agencies'. The family should continue to be fully supported by the team whilst the matter is being resolved. The care of the child must remain the main focus for all concerned.

3.3.6 Medical input

The involvement of another senior clinician may help in the communication of bad news or in decision making. In some cases obtaining second medical opinions will be advisable (see 'Obtaining second opinions'). These may involve matters of fact concerning the child's condition, prognosis and treatment options and their outcomes. They may be provided from within the unit/hospital or by outside independent expert(s). The latter is (are) advisable in cases where there are fundamental disagreements between the family and the team, where there has been an erosion of trust and where differences in the values of the parties produce disagreements over what should be done.

A medical second opinion could be organised by the consultant responsible for the care of the child. However, 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 or, if appropriate, with a representative from PALS. The family should be at liberty to change clinician and move to another consultant if this is possible.

Support from external agencies

In a relatively small number of cases, disagreement over treatment decisions may lead to escalating conflict. In such cases, external advice and/or conciliation from one of a number of sources may prove helpful to the parties. The engagement of a number of supportive groups, such as Clinical Ethics Committees (CECs), Hospital Chaplaincy and PALS, has helped avert many potential court hearings.

A. Clinical Ethics Committees

Continuing moral uncertainty as to the right course of action may lead to a request for an independent ethical review. In the UK, the most likely means of providing such a review is from a CEC or, more rarely, from an ethics consultation service. The function of CECs may include discussion, analysis and advice on individual cases, as well as contribution to policy making, teaching, training and research.⁸²

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 (child) concerned and good relationships between those involved. The function of an ethics support service in individual case reviews is to analyse the ethical dilemma(s) involved in order to help parties understand the relevant facts and differing values and to try to achieve better understanding between the parties involved. They may also have important mediation and conciliatory functions and may serve to protect patients' rights. Outcomes of such discussions should form part of the child's clinical record.

In current UK practice acceptance of any recommendation by a CEC/Service is optional. Any UK CEC/Service needs to retain its independence so as to maintain its moral integrity and arrangements for this need to be built into any formal provision of ethics support.

B. Chaplaincy/religious leader

Where issues have religious or cultural components, religious and out-of-hospital leaders can be helpful for families and hospital staff in recognising and resolving them.

C. Patient Advice and Liaison Service

PALS are a central part of the new system of Patient and Public Involvement (PPI) in England.⁸³ They are available in all NHS Trusts. Services provided by PALS include:

- ▶ Confidential advice and support to patients, families and carers.
- ▶ Information on the NHS and health-related matters.
- ▶ Confidential assistance in resolving problems and concerns quickly.
- ▶ Information on and explanations of NHS complaints procedures and how to get in touch with someone who can help.
- ▶ A focal point for feedback from patients to inform service developments.
- ▶ An early warning system for NHS Trusts, Clinical Commissioning Groups and PPI Forums by monitoring trends and gaps in services and reporting these to the Trust management for action.

D. Alternative Dispute Resolution and mediation

Alternative Dispute Resolution (ADR) services are increasingly used to address disputes over such matters as access and custody agreements that come before Family Courts. They include mediation services and these are currently being trialled in disputes about end-of-life care.

E. Legal input

In most cases, the healthcare team and parents will come to agree over a course of action. If agreement cannot be reached, legal advice should be sought from specialist healthcare lawyers. Every Trust will have an in-house solicitor, legal advisor or member of the Governance Team who will be able to provide initial advice. Another source of advice is the Children and Family Court Advisory and Support Service (CAFCASS) who can be contacted by telephone. The hospital should facilitate access to independent legal representation.

Taking legal advice does not necessarily mean that court proceedings will follow. If court intervention is considered necessary, the parents or their representative should be notified as soon as possible of any intended action. Decisions as to what treatment is in a child's best interests will be heard by a Judge in the Family Division of the High Court. At such a hearing parents will, if they choose (not all families want to be heard or represented), be able to express their own views and seek alternative opinion(s). The court will wish to ensure that the parents have had the opportunity to seek independent representation and to seek a second opinion should they wish to do so.

Although a duty Judge is available to hear applications at any time (even by telephone) this does not negate a duty on clinicians to seek the court's involvement in a timely manner and as early as possible (see 'The role of the courts in end-of-life decision making'). Emergency applications, where the team could have reasonably foreseen the need for an application, may attract adverse comments.

4. BEREAVEMENT

4.1 Families

Professional duties and responsibilities do not cease when a child dies. 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.^{84 85}

Each site where deaths of children occur should have specific policies in place which provide guidance for staff in addressing the needs of bereaved families and which describe the procedures that need to be followed when a child dies. This information should be readily available to all who require it. It should include details about asking for post-mortems, the needs of different religions, beliefs and cultures and the provision of mementos for the family. There should be practical guidance on the steps that families will need to take for registering the death and making funeral arrangements.

An offer of follow-up should be made to all parents of a child who has died. Follow-up should be provided to all those who accept it; it may be most helpfully provided by a home visit. Establishing contact between 1 and 2 months after the death gives the opportunity to discuss the results of a post-mortem or other investigations which may shed more light on the precise cause of death. Such contact also allows professionals 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 over-medicalisation of it should be avoided. Many families will find their own support in different ways and at different times. Families should be given access to information sources that enable them to make appropriate choices from the support and other services that are available. More counselling from support organisations or other forms of therapy can be offered to families requesting such help.

4.2 The healthcare team

Members of healthcare teams will also 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 within the team.

Many team members may themselves need support, but may have difficulties in acknowledging their needs or accessing services. 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 more junior members of the team. Certain groups, for example, night staff, may be specifically vulnerable or even unintentionally omitted from such discussions. Each person has different needs, which may be met in a variety of formal and informal networks and support systems. 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 with these issues appropriately 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 healthcare delivery.

4.3 Key goals in the provision of bereavement support

- ▶ The family should be allowed time and privacy with their child.
- ▶ Parents should feel in control of events before and after death and should be able to follow their own choices and wishes.
- ▶ Bereavement support should be offered, based on assessed needs.
- ▶ The bereavement needs of siblings should be recognised and support provided.
- ▶ The parents may want details of those they can contact to discuss any plans for future pregnancy; they may require referral to a specific genetic service.
- ▶ The needs of care staff should be considered, including supporting staff in ending their involvement with the family as part of an agreed bereavement plan.
- ▶ Staff support is essential and debriefing and ongoing support and supervision should be readily available.
- ▶ Communication with all persons and agencies providing bereavement services is essential.

Details or resources that may be useful in addressing the issues raised by bereavement are given in appendix 1.

5. FUTURE PRACTICALITIES

5.1 Training

All healthcare professionals should have access to continuing education in communication, ethics and law for example, MCA, Equality Act, especially as they pertain to withholding, withdrawing and limiting LST. Although these topics do form part of undergraduate training for all clinical disciplines, there remains a need for continuing professional development, according to principles established in professional guidance, for example, from GMC, Nursing and Midwifery Council, British Medical Association, Royal College of Nursing, Royal College of Midwives and other professional bodies. Ongoing delivery of training and the facility to reflect on challenging issues are key elements of good clinical practice. It is essential that the psychological and spiritual dimensions of care continue to be fully considered. Hospitals may also consider having an educational clinical ethics forum that periodically meets to review difficult cases or establish other mechanisms for this purpose. Child bereavement organisations and parent support groups could also have a useful role in providing such training. 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. In the current financial climate, offering expensive treatment inevitably uses funds that may be better used elsewhere. Debates about the fair allocation of scarce resources will increasingly form a backdrop against which treatment decisions are made. The ELAC-RCPCH do not feel that decisions about which child is offered intensive care should be resource motivated but should be determined by whether such care is appropriate, but they accept the need for further debate and greater transparency over questions of resource allocation.

5.3 Research/audit

In units and departments where complex treatment decisions have to be made it is important that the process of decision

making is subject to review and that the process conforms to principles of good clinical governance. In particular, it is helpful to have feedback from affected families on an ongoing basis.

Children's ability to cope with distressing news and their ability to make decisions should continue to be assessed by appropriate research. More focus will be needed on ways of communication that involve relevant developing technologies. This may be particularly important in ensuring that the voice of those with disabilities and their carers form part on ongoing treatment dialogues.

The UK Census⁸⁶ has confirmed that 1 in 10 children are classed as from minority ethnic groups and therefore decisions on limitation of treatment need to be underpinned by an understanding of cultural 'diversity'. This remains a relatively under-researched area, but is important in the face of increasing cultural diversity in the UK.

5.4 Clinical ethics services

There is agreement that support, guidance, teaching and training in the sensitive areas we have described are required for all staff. But there is 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 both the necessary impetus and the tools to accomplish this task. The establishment of a UK Clinical Ethics Network⁸⁷ has provided a forum for exchange of ideas, methodologies and protocols and also support for those attempting to establish, maintain or validate their services.

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- 87 For more details on UK Clinical Ethics Committees and networks. <http://www.ukcen.net>

Appendix 1

SUGGESTED BEREAVEMENT RESOURCES

Babyloss

A website service providing online information and support for anyone affected by the death of a baby during pregnancy, at birth or shortly afterwards.

<http://www.babyloss.com>

Email: support@babyloss.com

Child Bereavement UK

Child Bereavement UK supports families and educates professionals when a baby or child of any age dies or is dying, or when a child is facing bereavement. In addition to telephone and e mail support, they run groups for bereaved children and their carers and (in some areas) are able to provide individual face-to-face support.

<http://www.childbereavementuk.org>

Freephone helpline: 0800 02 888 40

Email: support@childbereavementuk.org

Childhood Bereavement Network

The Childhood Bereavement Network (CBN) seeks to ensure that all children and young people in the UK, together with their families and other care givers, including professional carers, can access a choice of high quality local and national information, guidance and support.

<http://www.childhoodbereavementnetwork.org.uk>

Cruse Bereavement Care Youth Line RD4U

Cruse's young people's website, designed by young people for young people (aimed at young people mainly between 12 and 18 years old).

<http://www.rd4u.org.uk>

Freephone Helpline: 0808 808 1677

Email: info@rd4u.org.uk

Child death helpline

Helpline for anyone affected by the death of a child of any age, under any circumstances, however long ago. Staffed by trained volunteers, all of whom are bereaved parents.

<http://www.childdeathhelpline.org.uk>

Freephone helpline: 0800 282 986 or 0808 800 6019 (for mobile phones)

Email: contact@childdeathhelpline.org

The Compassionate Friends

The Compassionate Friends (TCF) is a charitable organisation of bereaved parents, siblings and grandparents dedicated to the support and care of other bereaved parents, siblings, and

grandparents who have suffered the death of a child/children. Available for support and information daily. The line is always answered by a bereaved parent.

<http://www.tcf.org.uk>. This includes a website for bereaved siblings

National UK helpline: 0845 123 2304

Northern Ireland Helpline: 0288 77 88 016

Grief Encounter

Grief Encounter provides bereavement support for children, young people and adults. They are a child focused, open access specialist bereavement service providing support via their website, helpline, e-counselling, one-to-one support and residential camps

<http://www.griefencounter.org.uk>

Tel: 020 8371 8455

Email: support@griefencounter.org.uk

The Lullaby Trust

The Lullaby Trust provides specialist support for bereaved families and anyone affected by a sudden infant death. The Helpline offers the support of befrienders, who are themselves bereaved parents, grandparents and other relatives. Support can be arranged via the Helpline, usually by phone or email, although face-to-face meetings may also be possible.

<http://www.thelullabytrust.org.uk>

Freephone helpline: 0808 802 6868

Email: support@lullabytrust.org.uk

Sands—Still Birth and Neonatal Death Society

Sands offer support to anyone affected by the death of a baby before, during or shortly after birth. They offer emotional support and information for parents, grandparents, siblings, children, families and friends, health professionals and others. Support is available through the telephone helpline, e mail support groups, Sands groups and an online forum.

Website: <http://www.uk-sands.org>

National helpline: 020 7436 5881 (9.30–17.30 Monday–Friday)

Email: helpline@uk-sands.org

Winston's Wish

Winston's Wish can offer a range of practical support to children, families, professionals and anyone concerned about a bereaved child. They can provide support in individual, group and residential settings via their national helpline, interactive website and publications.

Website: <http://www.winstonswish.org>

National helpline: 08452 03 04 05

Email: info@winstonswish.org.uk

(All the above information is correct at time of going to press)