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

What does it mean for infants?

All healthcare professionals must have the care of their patients as their first concern. This duty of care is often expressed as a duty to act in the best interests of the patient. Practically this involves offering treatment that is intended to provide overall benefit while respecting the right of those patients who are able to do so, to make freely informed choices and respecting the patients’ wishes, beliefs and values. In the case of infants who cannot make choices for themselves the duty of care is exercised in partnership with parents. The views of parents in determining what treatment their infant will receive carry considerable weight provided that they too act in the best interests of their baby. Nevertheless decision making for very sick children can be complicated and challenging for their families as well as for the nurses and doctors caring for them.

During recent decades, advances in perinatal medicine, including the care of premature newborns, cooling for birth asphyxia and surgery for congenital malformations, mean even very unwell babies often go on to become healthy children and then adults. However for some infants, the continuation of life-sustaining treatments effectively prolongs suffering because no treatment is going to cure them. This means their quality of life is almost non-existent. In these cases, an active decision is reached among the healthcare team and parents involved to discontinue treatment, rather than cause greater suffering.

The new publication Making decisions to limit treatment in life-limiting and life-threatening conditions in children, developed by the Royal College of Paediatrics and Child Health (RCPCH), gives doctors making tough decisions on end-of-life care, an ethical and legal framework to help guide them through this difficult process.

The document is not meant to be a guideline or a protocol, but rather a framework to help teams engage with children and their families in an open, transparent and compassionate way about the really hard question of when treatment might not be the right thing for a sick child.

Life-limiting conditions are those in which there is no reasonable hope of cure, whereas life-threatening conditions are when curative treatment is feasible but may fail. Treatments in these contexts can either be withheld, which means not given or commenced; withdrawn, meaning stopped or removed; or limited, which means an agreed maximum level of intervention is set. For example, the maximum pressure a ventilator might be set at could be 30mmHg.

The major changes from the previous iterations are:

- increased recognition of the crucial role of palliative care in the end-of-life care for children in any environment
- positive acceptance of the role of shared decision making together with children and their families
- the appearance of organ donation as a routine consideration in end-of-life care
- a change of the categories describing when decisions to limit treatment may be considered:
  - when life is limited in quantity
  - when life is limited in quality
  - when a competent child makes this decision with support from the family and clinical team.

All of these, with the exception of the ‘competent child’ are relevant to those caring for infants, including those on neonatal intensive care units (NICUs). Two of the three situations, therefore, where it may be ethical and legal to consider withdrawing or withholding treatment apply to infants:

1. 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 interest to provide it.
2. 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 the illness itself and/or the treatment(s) involved.

A wide range of treatments may be withheld, withdrawn or limited if it is in an infant’s best interest to do so. In the NICU context such treatments include mechanical ventilation, intravenous inotropes or renal replacement therapy, as well as the more familiar cardiopulmonary resuscitation. More general therapies such as antibiotics or clinically assisted nutrition and hydration may also be involved, as may experimental therapies not validated by research.

Clear dialogue with parents and families is crucial in this area. The duty of candour and need...
to provide compassionate health care for patients is, of course, reflected in the daily honest and caring interactions in diverse healthcare environments between those caring for sick infants and their parents. Usually an agreed way forward that is in the best interests of the sickest children can be arrived at following open and transparent discussion. Occasionally such agreement cannot be reached and the framework therefore describes processes that can be helpful in such circumstances: clinical ethics committees, second opinions from other centres, interaction with advocates such as religious experts or even asking a court to determine what is in a baby’s best interest. None of this should either replace or prevent ongoing thoughtful dialogue with the family, which can be hugely assisted by hospital patient advice and liaison services.

Recent advances in this area include an increasing interface between palliative care services and NICUs, organ donation increasingly becoming a realistic option for the bereaved families of dying infants and the increasing role of groups such as Bliss.

The recent Nuffield Council on Bioethics report *Children and clinical research: ethical issues* has highlighted the paucity of research underpinning care of sick children and this is certainly the case in the area of decisions to limit treatment in infants. The RCPCH hopes its framework will be of use to doctors and nurses looking after the sickest infants and their families and encourages healthcare professionals to describe their work and undertake research in this area.

**References**