Resources to support the withdrawal of life-sustaining treatment

Withdrawing life-sustaining treatment is one of the most difficult areas of clinical practice that professionals face and finding the right way to open up this dialogue with parents can be daunting. UK children's palliative care charity ACT has launched two resources to support professionals caring for children at the end of life and to guide parents who are faced with thinking about the right critical care choice for their child.

'*A care pathway to support extubation within a children's palliative care framework*' and '*A parent's guide: making critical care choices for your child*' have been supported by the Department of Health.

The guide for professionals covers the journey towards a decision and the practicalities of withdrawing life-sustaining ventilation, and care at the time of death.

The resources can be downloaded free at: www.act.org.uk/extubation and www.act.org.uk/criticalcare or you can order free printed copies by emailing info@act.org.uk.

Guidance for the investigation of infants who suffer a sudden and unexpected postnatal collapse

The British Paediatric Surveillance study of sudden and unexpected postnatal collapse found that such events occur in healthy infants at a frequency of 1/19,000 term births in the UK. Given the rarity of cases in any one centre and the relative lack of published literature, it is recognised that clinicians can find it difficult to plan the most appropriate investigations to find an underlying cause for the collapse. Although they occur suddenly and unexpectedly, such cases are not usually considered under protocols for investigation in infants dying from sudden unexpected death in infancy (SUDI).

WellChild, a professional multidisciplinary group, has funded and developed guidelines specifically for the investigation of infants who suffer a sudden and unexpected collapse in the first week of life. These guidelines are not intended to replace the current RCPCH guidance for SUDI but aim to improve the likelihood of diagnosis.

Summary of recommendations

- Infants who suffer a sudden and unexpected cardiorespiratory collapse within the first week of life should be recognised as having an increased risk of congenital anomaly or metabolic disease as an underlying cause for their collapse.
- All such infants should also undergo comprehensive investigation to determine the underlying cause.
- Such an investigatory process will involve interdisciplinary liaison to maximise diagnostic yield while minimising unnecessary tests for the child.
- A detailed history of the family and situational events is essential and should be obtained by a senior member of medical staff.
- All infants who die from such collapse should be notified to a coroner/ procurator fiscal.
- All infants who die from SUDI should undergo post-mortem performed by a perinatal pathologist.
- A detailed multiprofessional case review should follow the investigation of any unexpected infant death.

Guidelines available on the website of the British Association of Perinatal Medicine: www.bapm.org/media/documents/SUPC%20Guidelines%20_2_.pdf. Hard copy publication or further information: Dr Julie-Clare Becher, email: julie-clare.becher@luht.scot.nhs.uk

New director at the NPEU

In March, Professor Ray Fitzpatrick, Head of the Department Public Health, University of Oxford, announced the appointment of Dr Jenny Kurinczuk as Director of the National Perinatal Epidemiology Unit. Dr Kurinczuk will become the fifth Director of the NPEU since its inception in 1978. She will also become Co-Director of the Policy Research Unit in Maternal Health and Care, funded by the DH and recently awarded to the NPEU team.

Professor Fitzpatrick says: "I am delighted that Jenny has accepted the post of Director of the NPEU. She has already been working very hard to ensure a smooth transition as the unit moves forward."

Jenny Kurinczuk, who takes over directorship from Professor Peter Brocklehurst following his move to University College London, graduated in medicine from Leicester University in 1985. Following post-graduate training in epidemiology and Public Health Medicine she was appointed Lecturer in Epidemiology at Leicester University and embarked upon her doctoral research on occupationally related male infertility. She then spent seven years working at the Telethon Institute for Child Health Research in Western Australia.

She joined the NPEU in October 2003 as Consultant Clinical Epidemiologist and was promoted to Deputy Director of the Unit and Reader in Perinatal Epidemiology in 2008. Her research expertise lies particularly in the areas of the causes and consequences of neonatal encephalopathy, cerebral palsy and congenital anomalies, and the health outcomes for children born following assisted conception. She is also involved in leading national studies of near miss maternal morbidity and the evaluation of paediatric surgical interventions for congenital anomalies.

Global neonatal transfers now a reality

AirMed, a UK-based specialist air ambulance operator, has set up a global neonatal transfer service called AM AirBorn, led by neonatal medical director, Dr Charlotte Bennett, who is a consultant neonatologist at the Oxford Radcliffe Hospitals NHS Trust.

Jane Topliss, Business Development Manager at AirMed, says: "A team of nurses and doctors, already experienced in land-based transfers, have completed a rigorous and bespoke aeromedical training course. The service provides rapid access to specialist advice on clinical safety, family support and strategic planning, allowing safe transfers to be pre-planned and carried out during the ideal window of opportunity."

The equipment, which has been designed and purchased by AirMed, is fully compatible, not only on its Learjet 35A and Piper Cheyenne IIIA fleets, but also with the UK HEMS EC135s and road ambulances. The system currently in use following completion of phase one includes a Babypod II, babyPAC ventilators, Propac monitors and Braun infusion pumps in addition to the existing intensive care equipment currently operated by AirMed.

Lisa Moran, one of the leading transfer nurses associated with the AM AirBorn service.

Development of the AM AirBorn service is ongoing and AirMed is planning completion of phase 2 by the end of 2011. Jane explains: "This will lead to a further expansion in capabilities and will see the addition of a Drager incubator, a custom-built trolley and lift system currently being designed and built by Paraid. PrinterNoX inhaled nitric oxide delivery will also be added.

"Not only will this enable AM AirBorn to carry out transfers of the most critically ill neonates, but the additional system will also allow twins to be transferred together."

Dr Bennett is supported by Dr Julian Eason, a fellow consultant neonatologist who is currently service line director for the neonatal department at Plymouth Hospitals NHS Trust.

Comment from stillbirth and neonatal death charity Sands...

UK stillbirth rate

According to a 'Series on Stillbirth' report in the Lancet, the UK has one of the worst stillbirth rates (3.5 stillbirths per 1,000 births for deaths in the third trimester) compared with similar high income nations with similar populations.

Eleven babies are stillborn every day in the UK and a significant proportion of these deaths are potentially preventable. Most babies who are stillborn do not have any serious abnormality and a third of stillbirths have no obvious cause. Sub-optimal maternity care has been found to contribute to over half of otherwise unexplained stillbirths. Sands believes that too many stillbirths are under-investigated, meaning lessons are not learned, practice does not change, and parents are left without answers as to why their baby died. Sands would like to see:

- Women informed that risk factors such as obesity, smoking, alcohol consumption and being over 35 years of age all increase the risk of a stillbirth.
- Better information about warning signs that a baby may not be thriving, such as fetal movements slowing down.
- Appropriate training for healthcare staff so they are fully aware of the risk factors and warning signs for stillbirth and know best practice for how to respond.
- Rigorous investigations into the cause of stillbirths in the UK to identify changes in practice.

Access the full 'Series on Stillbirth' at www.thelancet.com/series/stillbirth

New audit tool to improve bereavement care

The audit tool 'Caring for parents whose baby has died' has been developed by Sands to help those responsible for commissioning and providing maternity services to assess the quality of care they provide to bereaved parents and identify improvements needed.

Accredited by the Royal College of Midwives, the audit tool is based on standards set out by Sands in 'Guidelines for Professionals' (2007) and by a range of professional organisations including the Royal College of Obstetricians, the Royal College of Pathologists, NICE and the Human Tissue Authority.

Sands Improving Bereavement Care Manager Judith Schott, co-author of the audit tool, explains: "The care parents receive when their baby dies cannot remove their grief and pain but poor or insensitive care can exacerbate their distress. The Sands audit tool will help maternity service managers and staff to ensure that bereavement care services in place at any given hospital are as good as they possibly can be."

Judith continues: "Sands recognises that while some improvements identified by the Audit Tool may carry a major cost, small changes in the way care is organised and provided can often make a huge difference to parents' experiences.

For more information, access www.uk-sands.org or email info@uk-sand.org