

Doctors need not ventilate baby to prolong his life

Clare Dyer
legal correspondent, *BMJ*

Doctors caring for a terminally ill baby with a chromosomal disorder need not provide mechanical ventilation to prolong his life, the senior family judge for England and Wales ruled last week.

The case of 9 month old Luke Winston-Jones is the second battle between parents and doctors over the treatment of a baby with a limited life expectancy to reach the High Court in the last month.

Both Luke's mother and the parents of 12 month old Charlotte Wyatt described their infants as "fighters" because both had lived longer than doctors had predicted, and both sets of parents argued that mechanical ventilation should not be ruled out.

Luke's mother, Ruth, also wanted the possibility of cardiac massage left open for her son, who has Edwards' syndrome or trisomy 18 syndrome, a condition severely affecting most of his organs. Few babies with the dis-

order survive beyond a year.

The Liverpool Royal Children's NHS Trust, which is treating Luke at Alder Hey Hospital, and his home trust, North West Wales NHS Trust, sought a court declaration that neither mechanical ventilation nor cardiac massage would be in Luke's best interests.

Dame Elizabeth ruled that Luke should not be mechanically ventilated, but after the trusts withdrew their application for a declaration ruling out cardiac massage that option was left open.

Dame Elizabeth said mechanical ventilation would be against Luke's interests because it was highly likely he would become dependent on the ventilator, depriving him of his mother's cuddles for the rest of his short life. Expert evidence was that his chances of dependency were 75% to 100%.

She said it would be up to doctors' clinical judgment whether to provide cardiac massage if the occasion arose.

She called for an end to the conflict between mother and doctors. "It is the duty of the mother for the sake of Luke to reduce areas of conflict to a minimum and listen to what is proposed by those who have a great deal of medical and nursing experience."



Ruth Winston-Jones described her son, Luke, as "a fighter" because he has survived longer than doctors had predicted

The judge said: "It is important that everyone in this case, both hospitals and particularly the mother and her family, who have been so supportive of her, should turn over a new leaf and move forward." The mother must "accept the clinical judgment of the doctors who are caring for her child," she added.

Earlier this month Mr Justice Hedley ruled that mechanical ventilation would not be in the best interests of Charlotte Wyatt, a profoundly handicapped baby born three months prematurely (*BMJ* 2004;329:875, 16 October).

The two NHS trusts said they were "very satisfied" with the ruling. □

NICE guidance on epilepsy recommends specialist diagnosis

Susan Mayor *London*

All patients suspected of having seizures should be seen urgently by a specialist for diagnosis and be given individually tailored treatment, recommends a new guideline published this week. The guideline is designed to improve the care in the NHS of children and adults in England and Wales with epilepsy and to reduce the number of sudden deaths associated with epilepsy.

The guideline was published by the National Institute for Clinical Excellence (NICE), which provides national guidance on treatments and care for the NHS in England and Wales, and the National Collaborating Centre for Primary Care.

It complements recent guidance from NICE on the use of newer antiepileptic drugs and is

designed to achieve accurate and timely diagnosis, improve communication, and provide regular reviews of treatments. The new guideline recommends that anyone with recent onset of suspected seizures should be seen urgently by a specialist to ensure precise and early diagnosis and initiation of treatment.

Drug treatment should be tailored to type of seizures, epilepsy syndrome, other drugs being taken, comorbidity, and individual lifestyle factors and preferences.

Individuals with epilepsy and their carers should be partners in all decisions about their health care, the guideline suggests. To facilitate this everyone with epilepsy should have a

comprehensive care plan that is agreed between the patients, their family or carers, and primary and secondary care doctors.

They should have regular, structured review at least yearly. Patients should be referred to a tertiary service as soon as possible if their seizures are not controlled or there is uncertainty about their diagnosis or treatment failure.

The evidence base for the guideline included an audit across the United Kingdom of sudden unexplained death in epilepsy that was carried out in 2002, led by the charity Epilepsy Bereaved and funded by NICE. Nearly half of the 1000 deaths that occur in the United Kingdom each year as a result of epilepsy are sudden and unexpected.

The audit found that 59% of deaths among children and 39% of deaths among adults could potentially, or probably, be avoided. The main risk factor was ongoing seizures.

Jane Hanna, director of

Epilepsy Bereaved and a member of the guideline development group, said: "We hope that these guidelines will be put into practice at a local level so that people with epilepsy have a choice to be seizure free and unnecessary deaths are avoided."

Professor John Duncan, professor of neurology at the National Hospital for Neurology and Neurosurgery, London, and a member of the guideline development group, said: "Of particular importance are the needs to establish a correct diagnosis and, if treatment is unsuccessful, to keep the diagnosis under critical review and to consider referral for a further specialist opinion, timely and accurate information provision, and the integration of medical and social care." □

Epilepsy: The Diagnosis and Management of Epilepsy in Children and Adults can be found at www.nice.org.uk