

New research highlights childhood death taboo

New research has revealed that one in four of the British public find anything to do with childhood death too distressing to talk about as the subject is too emotional. The Association of Children's Hospices, which commissioned the research, is concerned that fundraising efforts and access to children's hospices by those who need their help are affected by these taboos.

The research, carried out to mark Children's Hospice Week in September, found that the "switch off" factor is particularly acute among parents – more than six out of ten people (61%) with children under the age of 16 said seeing coverage in the media depicting children seriously ill or dying makes them feel vulnerable about their own children/grandchildren.

"There are an estimated 20,000 life-limited children in the UK. Because of these taboos many families don't want to make use of children's hospices," said Barbara Gelb, chief executive of the Association of Children's Hospices. "Moreover families with life-limited children often feel isolated from the community and unable to share their experiences with friends and other relatives



Thomas enjoying a painting session at Christopher's Hospice in Guildford.

who feel uncomfortable discussing the issue. And fundraising efforts by children's hospices may well be affected by individuals and companies switching off and not wanting to know."

Ms Gelb continued: "We want to let children and families know that help is at hand through children's hospice services and that they are places of happiness and fun – lifelines to the children and families who rely on them".

www.childhospice.org.uk

Childcare course fills a gap in training for long-term carers

Advances in medicine have resulted in an increasing number of children who have complex health needs requiring long term intervention and this population has traditionally been cared for in hospitals and ICUs. However, it is now seen as appropriate to promote an environment where these children can be cared for in their family unit.

Although such care is overseen by a registered nurse, healthcare support workers often provide a significant amount of the day-to-day care even though specific training for these workers has until now been in service and *ad hoc*. The Certificate in Higher Education, Caring for Children with Complex and Continuing Health Needs has been developed by Clinovia Ltd and the Institute of Health and Community Studies at Bournemouth University in order to address this.

The distance-learning course, which has been validated with Bournemouth University, is part-time over two years and consists of six work-based learning units as well as some study days. A Certificate of Education will be issued on successful completion of the course.

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A consistent approach to cot death advice is needed

The Foundation for the Study of Infant Deaths (FSID), with support from Grobag, has carried out an opinion poll of 162 new parents about whether their midwife or health visitor discussed how to reduce the risk of cot death. Nearly one third of parents (31%) said that they had not, or that they had no recollection of a discussion. There are large regional variations with, for example, 54% in London recalling a discussion compared with 87% in the North of England.

Other findings show that many health professionals are discussing the advice too late. Less than half (49%) of parents who did recall a discussion reported that it took place during the pregnancy, yet it is important to discuss the advice at that stage so parents can know to cut smoking, what bedding is safe to buy and to sleep baby on the back from day one.

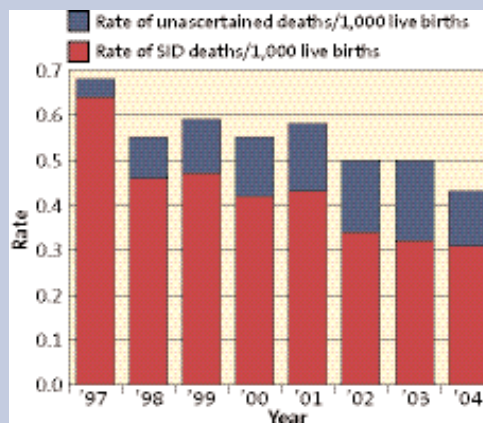
FSID has created a colourful cartoon-style sticker designed to be stuck on parent-held notes for pregnant women, on hospital cots



and on parent-held baby health notes. The aim is to complement the work of health professionals and remind them to discuss this essential advice. The stickers are being sent to maternity units and Sure Start programme centres across

England, Wales and Northern Ireland. The announcement of the collaboration between FSID and Grobag followed the release of figures from The Office of National Statistics (Aug 2005) which showed that 313 babies died suddenly and unexpectedly for no apparent reason in the UK in 2004. This marks a 12.6% fall compared with the previous year's figures. While the news is welcome, FSID believes that more research is needed to explain these deaths and provide more ways to reduce the risks of cot death.

FSID helpline 0870 787 0554.



Commissioner puts pain management in children at the forefront

The Children's Commissioner is calling on the NHS to implement the pain management standards recommended in the 2004 National Service Framework for Children, Young People and Maternity Services. Professor Al Aynsley-Green wants to see pain management prioritised within the NHS and stresses the need for a better understanding of child pain management particularly when children are outside traditional paediatric environments.

Al Aynsley-Green commented: "I know from my own research that children feel pain from a very early age. August's Healthcare Commission review revealed that 47% of children admitted to A&E with broken limbs were not offered pain relief within an hour of being admitted to hospital. We also know that children are often not receiving adequate and basic pre-hospital relief from pain and distress in ambulances.

"These failures reflect shortcomings in recognising children's ability to experience pain; fears of the side effects of analgesics and anaesthetics in children; and lack of resources to train clinicians.



Bede uses a pain assessment tool to help staff at Great Ormond Street manage his pain during multiple surgeries for hypoplastic left heart syndrome.

"We know that children's early experience of health affects their attitude to the health service for the rest of their lives. I want to see health professionals better trained in pain assessment and treatment techniques that specifically meet children's needs. More investment is needed in funding for research on children's pain as well as the systems and resources, particularly staff, to put research findings into practice."

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Winners of the 2005 Novartis and The Daily Telegraph Visions of Science Photographic Awards, supported by the Science Photo Library, included this image of a father and his baby. "Kangaroo care of premature baby" by Tina Stallard won second place in the people category.

Under development: Vaccine against GBS for newborns

Microbiologists from the University of Bradford believe they may be closer to developing a vaccine that can protect newborn babies from being infected by the common and potentially fatal bacteria Group B Streptococcus (GBS).

GBS is the most common bacteria attacking newborn babies, affecting one in 1,000 births, and killing up to six per cent of those infected. It infects around 700 babies in the UK each year and kills around 100 of those infected, according to the national charity Group B Strep Support.

GBS can cause pneumonia, blood infections and meningitis, and seriously ill babies can die within 24 hours of birth. Babies catch the bacteria from colonised mothers around the time of delivery. Pregnant women may be unaware that they are carrying GBS as usually there are no symptoms.

Beverley Bray, a PhD student from the Department of Biomedical Sciences at the University of Bradford, is focussing her studies on this vaccine under the supervision of research leader Dr Dean Harrington.

Their research has focused on structures on the bacterium's surface – lipoproteins – which they think may be important in several processes, including attaching GBS to the baby's own cells.

Mrs Bray said: "At the moment, we don't know why GBS is so virulent, so we need to understand how it sticks itself to a baby's

cell surfaces to give us a chance of creating a vaccine. If we can develop an effective vaccine from lipoproteins, we could prevent colonised mothers from transmitting the bacteria to newborns. This should remove the need to treat large numbers of mothers and babies with antibiotics."

Group B Strep Support www.gbss.org.uk

Ask a midwife for advice via email

Mother and Baby Magazine has teamed up with www.midwivesonline.com to allow visitor's to their website to email a qualified midwife and receive a personal reply.

The 'Ask a Midwife' service supports parents between clinic visits with answers to non-urgent information.

Georgina Hersey, website managing editor, Mother and Baby Magazine, said: "By providing a service that can be accessed 24/7, we will provide our readers with peace of mind as their question will be answered by a trained midwife.

"Every response will be checked for quality and content by two midwives to ensure the best possible advice and we guarantee a reply within seven days."

Developed by Catharine Parker-Littler, a midwife of 20 years, the website was originally set up to provide midwives, neonatal nurses and health visitors with a portal to the latest information and research. It has now developed into a site providing unbiased advice from a team of 15 midwives, as well as news.