Experts discuss babies with an uncertain future

Eighth annual neonatal palliative and end-of-life care conference, London

With 15 babies being stillborn or dying during the neonatal period every day in the UK, the need for a high standard of neonatal palliative care has never been greater. National charity Child Bereavement UK holds an annual conference that addresses this issue and strives to improve awareness, confidence and skills among professionals working at the frontline of neonatal care.

Child Bereavement UK's eighth neonatal palliative and end-of-life care conference took place in London in February and, with over 200 attendees, was its largest conference so far.

A couple of overriding themes emerged from the conference:

- it's the little acts of kindness that make a big difference
- it's not always about talking; it's mostly listening.

FIGURE 1 Ethical issues in neonatal care – the debate panel. Tim Deeming (Principal Lawyer – Clinical Negligence, Slater and Gordon), Tom Sheldon (Senior Press Manager, Science Media Centre), Dominic Wilson, Alex Mancini, Róisín McKeon-Carter and Vic Robinson (Former Child Bereavement UK Chair of Trustees).

Ethical issues in neonatal care

Exploring the theme of 'babies with an uncertain future', experts in the field of neonatal and palliative care came together to discuss a range of topics. A panel discussion was held on ethical issues in neonatal care, which included Neonatal Consultant and Ethicist Dominic Wilkinson, Pan-London Lead Nurse for Neonatal Palliative Care Alex Mancini, and Senior Advanced Neonatal Nurse Practitioner and Clinical Director of Neonatology at Derriford Hospital Róisín McKeon-Carter (**FIGURE 1**).

The discussion included:

- babies born before 24 weeks' gestation and the opportunity for parents to have a birth/death certificate. This is very topical at the moment as the Department of Health and Social Care has recently funded a research project to look into this
- the impact on health professionals caring for babies when there is a conflict or difference of opinion between the team and the family
- the power of the media (particularly social media) in relation to recent high profile cases.

FIGURE 2 Left: Parent Sarah Collins with her daughter Isabel. Right: Isabel being christened in her incubator.

A mother's perspective

Child Bereavement UK's conferences always include the 'voice of the families', whose experiences are important in helping professionals to understand and meet their needs. This year conference delegates heard a very moving account from parent Sarah Collins, whose baby daughter Isabel (Izzy) survived a brain haemorrhage that resulted in a range of disabilities. In a presentation entitled 'My daughter's journey from neonatal intensive care and beyond', Sarah described how she and her family manage Izzy's ongoing and complex needs. Sarah's words helped to remind delegates that for some parents there is often a sense of loss and grief for the healthy full term baby that they were expecting.

Sarah said: "Nothing prepares you for the first time you enter a neonatal unit. My baby looked nothing like I had expected and she was hooked up to a hoard of mysterious noisy machines. She was extremely poorly. I didn't feel like a mum, I felt like I was a powerless visiting onlooker and I was terrified.

"I have a photo of Izzy being christened kindly taken by one of the lovely nurses (**FIGURE 2**). I never would have thought to take that photo; I was barely functioning. One of the things that stands out through our times in hospital is the kindness of people."

All Child Bereavement UK training is based on learning from bereaved families and recognises how appropriate communication and support from the outset can have positive and sustained benefits for their future wellbeing. Learning is underpinned by relevant theory and evidence-based practice, helping professionals to better meet the needs of bereaved families.

Student bursaries

Thirty student midwives who attended the conference were awarded bursary places courtesy of Abigail's Footsteps, a charity established in 2010 by David and Jo Ward following the death of their daughter Abigail, who was stillborn at 41 weeks' gestation (**FIGURE 3**). The charity's vision is to provide healthcare professionals with bereavement care training and support to ensure that bereaved parents receive the highest standard of care following the death of a much-loved baby. One delegate who benefited from a bursary place commented: "As a student midwife, this conference has enlightened me and empowered me to offer evidence-based, empathetic, professional care to parents."

Bereavement training for professionals

The conference celebrated a major milestone for Child Bereavement UK by marking the occasion of having trained over 100,000 professionals since the charity was launched 24 years ago. Founder Patron and author of *Grief Works: Stories of Life, Death and Surviving,*[1] Julia Samuel MBE, presented an award to the charity's 100,000th bereavement-trained professional Dr Georgia Ekitzidou, Associate Specialist in Neonatal Medicine at the Homerton Hospital in London (**FIGURE 4**).

FIGURE 3 Student midwives who attended Child Bereavement UK's conference with bursary funding from Abigail's Footsteps. Pictured with David Ward and Sam Collinge, Specialist Bereavement Midwife at Coventry University Hospital and trustee for Abigail's Footsteps (back row, centre).

FIGURE 4 Julia Samuel MBE and Dr Georgia Ekitzidou.

On presenting the award, Julia said: "When a baby is born, there is anticipation of new life and celebration, so nothing prepares parents for the shock of the news that their baby is very sick or dying. That is why bereavement training is so important. Professionals need the skills and confidence to give parents the best quality care and sensitive support at an extremely difficult time for everyone, so that families can begin to face their new circumstances and the difficult journey ahead."

Child Bereavement UK training workshops

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. Its vision is for all families to have the support they need to rebuild their lives. The aim is to ensure the accessibility of high quality child bereavement support and information to all families and professionals by increasing Child Bereavement UK's reach – plugging the gaps that exist in bereavement support and training across the country, and embedding standards in the sector. Information about training workshops for professionals can be found on the website at www.childbereavementuk.org/training. Upcoming events include:

- *The challenges of supporting parents through the neonatal experience.* Facilitated by Child Bereavement UK's Head of Training Paula Abramson and Alex Mancini, this workshop explores subjects such as sensitive communication, breaking bad news, the parents' lived experience and the most up-to-date research on neonatal palliative care.
- *When a twin dies – supporting parents and families.* This new workshop draws on current research and learning from the neonatal Butterfly Project.[2] It is suitable for any professional whose work brings them into contact with families grieving the loss of a twin.
- *Managing parents' expectations – building positive relationships.* The next Child Bereavement UK neonatal conference will be held in London on 5 February 2019. For further information visit www.childbereavementuk.org/conferences

References

1. **Samuel J.** Grief works: stories of life, death and surviving. Penguin Life; 2017.
2. **Embleton ND, Stephenson S, Campbell C, et al.** Butterfly Project: supporting parents who have lost a baby from a multiple pregnancy. Infant 2016;12:222-23.

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