



Spotlight on Sands

Issue 9

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ISA Conference 2014
special edition

In September, bereaved parents from around the world came together with internationally respected researchers into stillbirth and perinatal death for the 2014 conference of the International Stillbirth Alliance (ISA). Sands has been a longstanding supporter of ISA and the incomparable opportunity for learning and discussion that their annual meetings provide, and I'm delighted that we were able to sponsor this year's conference in Amsterdam.

Sands and ISA have a long history together. The organisations have similar roots: each was formed by a small group of bereaved parents determined to get the impact of a baby's death acknowledged and understood. The three US mums who started ISA in 2002 focused from the start on combining the knowledge of healthcare professionals with the passion of families to advance stillbirth research and medical care. Recognising the value of the Alliance, Sands joined the group early on, contributing to the Board and sub-committees.

The ISA 2006 conference in Japan was a turning point for Sands. We already knew that poor care was leading to avoidable deaths in the UK. In Kyoto we started to hear potential answers. We also began a dialogue with international stillbirth experts who we now, in 2014, regard as old friends. We co-hosted the 2007 conference with the Perinatal Institute in Birmingham, and led the bereavement-support tracks in subsequent conferences in South Africa and Antigua.

Our journey to make stillbirth reduction a health priority in the UK has been greatly shaped by ISA. The ISA-authored Lancet stillbirth series, published in 2011, has been hugely significant, showing that if other countries could improve their mortality rates, the UK could too. The fact that stillbirth reduction is now a priority in the UK owes much to the ISA community. We look forward to continuing our collaboration with ISA, not least supporting the 2015 Lancet Stillbirth update.

Neal Long, Chief Executive, Sands

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Diary Date

Lights of Love

Friday 5th December 2014

Please join us at one of our annual non-denominational Lights of Love carol services held across the country.

Visit our website www.uk-sands.org for more details.

Sands: Bringing about change in the UK

In the Sands session 'Bringing about change in the UK – a collaboration of parents and professionals', Ronnie Turner (Improving Bereavement Care Manager) introduced the international audience to Sands and its three aims of support for anyone affected by a baby's death, improving bereavement care, and promoting and supporting research and prevention. She talked about the leaflets, information and resources that Sands provides for parents and health professionals, and the annual Sands/Bliss/Royal College of Midwives conference that promotes good practice and learning in bereavement care in the UK.

Ronnie described how Sands has comprehensively revised the bereavement care training it offers for health professionals, following a wide-ranging review. The new training workshops combine the experience and voice of parents and professionals with statistics and evidence. Effective skills-based exercises help professionals develop their skills – particularly in communicating sensitively and effectively with bereaved parents. Feedback has been positive, with participants saying they feel more confident about providing high-quality care. The Sands training has also received professional accreditation from the Royal College of Midwives (RCM).

Gail Johnson, Education Advisor at the RCM, followed Ronnie onto the platform to give a personal and moving account of her career as a midwife and how she struggled to overcome her fear of communicating with bereaved parents. She described a memorable encounter with an expectant mum who had experienced a previous loss, who helped her to understand what kind of communication was helpful. Gail was very grateful for this experience and emphasised how parents and professionals need to work together to ensure that bereavement care continues to improve.



Charlotte Bevan, Sands Senior Research and Prevention Advisor

Charlotte Bevan (Senior Research and Prevention Advisor) gave the audience an insight into how the voice of parents has been key to supporting research and promoting the prevention of stillbirths and early neonatal deaths in the UK. She described the initiatives across all four UK countries with which Sands is involved, including the development of health messages for 'a safer pregnancy' and a web-based tool to guide a review by the clinical team when a baby dies.

Dr Catherine Calderwood (National Clinical Director for Maternity and Children's Health at NHS England) rounded off the session by describing how those seeking change need to "get into the mind of government." She advised those trying to influence policy to ask for small and big changes, to be flexible and to find a champion 'on the inside'.



Sands team at ISA 2014 from bottom: Erica Stewart, Bereavement Support Services Manager; **rows 2&3 from left to right:** Ed Ford, Sands Trustee; Charlotte Bevan, Senior Research and Prevention Advisor; Laura Price, Research & Information Officer; Judith Abela, Groups Manager; Neal Long, Chief Executive; **row 4 from left:** Ronnie Turner, Improving Bereavement Care Manager; Gail Johnson, Royal College of Midwives

"Bereaved parents can create the energy to inspire researchers and implement changes in real life." Adja Waelput, midwife involved in developing the Netherlands' nation-wide perinatal audit

Reducing perinatal deaths – the call for action

A drive for change resonated throughout the ISA conference, which kicked off with Professor David Ellwood, from Griffith University in Australia, reflecting on an academic watershed.

The ground-breaking Lancet series of scientific papers on stillbirth, published in 2011 and including one authored by Sands' Head of Research and Prevention, Janet Scott, sparked remarkable media interest, with its messages reaching an estimated one billion people worldwide. For the first time, stillbirth rates in high-income countries were compared – the UK's unchanging rate contrasting uncomfortably with the reductions seen in similar countries. The series also looked at the major causes of stillbirth and the research questions that needed answering.

Professor Vicky Flenady, from the University of Queensland, Australia, outlined some of the projects kick-started by the Lancet series.

- ▶ The World Health Organization (WHO) is now developing a global system for classifying the causes of stillbirth and early neonatal deaths – this will eventually replace the 62 different systems in use around the world, making information-sharing easier.
- ▶ Studies are under way in the UK, Australia and New Zealand to investigate whether highlighting the importance of baby's movements during pregnancy can save babies' lives without making women over-anxious. (Sands part funds the UK study, AFFIRM).
- ▶ Australia and New Zealand have launched IMproving Perinatal mortality Review and Outcomes Via Education (IMPROVE) workshops in hospitals and maternity units to train staff on bereavement care, communicating with parents about post-mortem, clinical examination, placental and post-mortem examination, investigation, classification and audit of stillbirth.



Joy Lawn speaking about the Every Newborn Action Plan: changing the future for the world's newborns and stillbirths

The next Lancet series is now in development. Linking with the WHO's *Every Newborn: an action plan to end preventable deaths*, it will look at progress in reducing stillbirths and perinatal deaths around the world, the cost of stillbirth (crucial for health service decision-makers) and more ways of reducing stillbirths in high-income countries such as the UK. And it will re-emphasise the goal of eliminating all preventable stillbirths and closing an equity gap that sees stillbirths happen more commonly in women from poorer backgrounds. Such progress will also reduce preventable early neonatal deaths, many of which happen for the same reasons as stillbirths.

The importance of the Lancet stillbirth series for those working to save babies' lives is unquestionable. But WHO still calls stillbirths "an invisible public health priority", and in the words of Professor Flenady, "we still have a long way to go." Parents, health professionals, researchers and charities need to keep pushing stillbirth and perinatal deaths to the fore.

"ISA, its international annual conference, and the Lancet Stillbirth Series which came out of ISA, is integral to raising the profile of stillbirth. We're able to meet, to network together to reduce stillbirths faster and improve care for parents. If we don't take it on in this way the issue will never be addressed. ISA is the tool we need to move on." Professor Vicky Flenady, Perinatal Epidemiologist, Mater Research Institute, University of Queensland, Australia

Research highlights from ISA 2014

Researchers in Manchester have looked at placentas from women who reported reduced fetal movements (RFM) during pregnancy. Placentas from women whose baby was stillborn or poorly at birth were smaller and measurably different from placentas that supported healthy babies. Placenta abnormalities are also being uncovered in some of the stillbirths currently classified as 'unexplained'. The Manchester team are now trying to find ways of identifying women whose placenta is showing signs of abnormality during pregnancy so that they can have additional monitoring and, if necessary, early delivery.

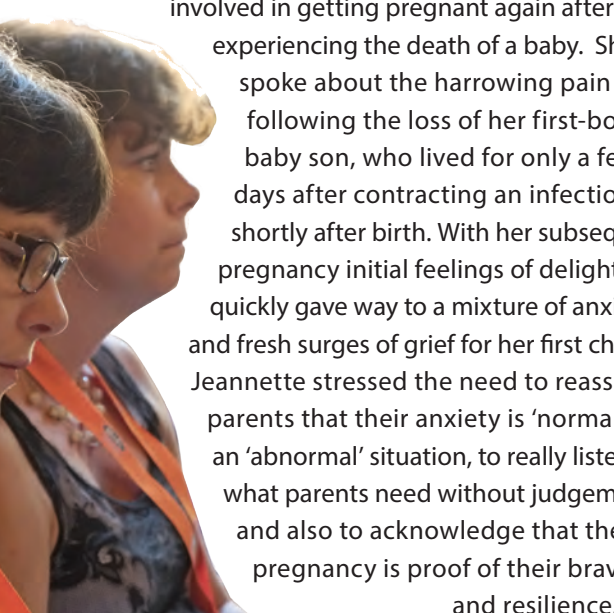
"We increasingly see a greater understanding of placental pathology and what areas of research we need to focus on. My hope is that in the future, if we're able to fix placental dysfunction, we'll be able to

tackle the problem of many stillbirths."

Professor Vicky Flenady, Perinatal Epidemiologist, Mater Research Institute, University of Queensland, Australia

Away from the laboratory, Diana Bond from the Sydney Stillbirth Study team, Australia, spoke passionately about the 'barriers' faced by researchers trying to involve recently bereaved parents in studies. A desire to protect families from additional distress means that research groups are often advised to leave a lengthy delay before approaching potential study participants. But the Sydney Stillbirth Study team asked bereaved parents about their anxiety and feelings about being asked to take part in research a matter of days after their baby had died. Overwhelmingly, the parents said they were pleased to have been asked to take part and that it hadn't caused them distress.

One child too few – the struggles of a subsequent pregnancy



Dutch bereaved parent and author, Jeannette Rietberg, gave a powerful talk about the enormous challenges involved in getting pregnant again after experiencing the death of a baby. She spoke about the harrowing pain following the loss of her first-born baby son, who lived for only a few days after contracting an infection shortly after birth. With her subsequent pregnancy initial feelings of delight quickly gave way to a mixture of anxiety and fresh surges of grief for her first child. Jeannette stressed the need to reassure parents that their anxiety is 'normal' in an 'abnormal' situation, to really listen to what parents need without judgement, and also to acknowledge that the pregnancy is proof of their bravery and resilience.

She listed 10 points (summarised below) to help health professionals care for bereaved parents throughout a subsequent pregnancy:

1. Know details of their previous loss
2. Communicate with empathy
3. Do not denigrate (minimise the loss)
4. Avoid using medical terminology
(use the term 'baby' or the baby's name)
5. If appropriate, acknowledge a parent's guilt as an expression of their sense of parental responsibility
6. Be aware of the thin line between grief and depression
7. Former malpractice damages trust in medical professionals, so:
 - ▶ Don't justify your colleague's actions
 - ▶ Be completely transparent
8. Encourage them to write a birth plan
9. Be aware of defence mechanisms such as:
 - ▶ Fencing off emotions
 - ▶ Avoiding any preparations for this baby
 - ▶ Concentrating on the pregnancy and not on the baby
10. Help them to control an uncontrollable situation by providing:
 - ▶ An individual medical plan
 - ▶ Continuous access to professionals
 - ▶ The option of check-ups on former due dates/ anniversaries etc.

Fathers' experiences

Fathers and Grief

Margaret Murphy from University College Cork presented her findings from a literature review looking at fathers' experiences of subsequent pregnancy after a loss.

The few studies on this subject suggest that fathers can become hyper vigilant in subsequent pregnancies, often wanting further reassurance through additional scanning. Fathers can become emotionally distant from the expected new baby until the baby is born.

Health professionals should be aware of the need for **both** parents to be supported, as often the focus is on Mum's clinical care.

David Borman, a midwife and teacher, trains men (without their partners) on transition to fatherhood.

Many fathers, including those who were not bereaved, felt insecure at the prospect of becoming a father, and this was even more evident for bereaved fathers who had huge anxiety as well. It is important that fathers are cared for in subsequent pregnancies.

Grieving fathers were expected to act differently, so were treated differently. In fact their responses are not that different from the way women express their grief. Emotions are the same but expressed at different times.

Brent Grant and his beautiful daughter Finnley

Multicultural views of stillbirth and minority ethnic experiences of bereavement care

Several sessions focused on the importance of considering multicultural issues in bereavement care. Interviews with bereaved parents were integral to the InSight study but researchers were unable to find any parents from a minority ethnic background who were willing to be interviewed, something they recognised was important to address in future studies.

Caroline Chebsey from the study raised the point that a one size fits all approach to maternity care can't be expected to work in our multicultural environment. Conversely, it can be very difficult to encompass all faiths and cultures when there are so many different views even within the same religion.

A discussion around post mortems and how this was viewed by different faiths again revealed differing perspectives, but the InSight study found that even though there may be a culturally-specific view, the general message was that most faiths supported the parents' right to choose.

Sessions on "Who tells a mother her baby has died", "Having a stillbirth and the support from the church" and "The spiritual impact of stillbirth on bereaved parents and obstetricians" also covered some of these issues. Discussions highlighted that while religion can offer meaning and support for some, for others the death of a baby can lead them to question their core beliefs.

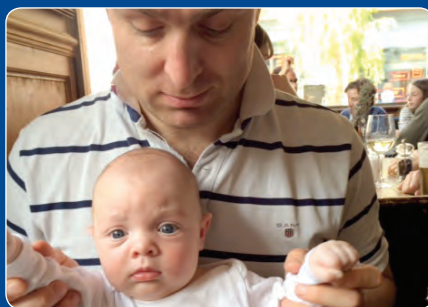
Parent perspective

Jennifer and Chris Reid's son, Edward Louis Reid, was born at 5am on 18 January 2014 – a healthy, big and strong baby *"the most perfect and amazing gift; the brightest light to ever shine in our lives"*. Tragically, 3 months later on 16 April 2014, Edward died, a victim of Sudden Infant Death Syndrome (SIDS). It was, says Jennifer, *"the most devastating loss imaginable"*. The parents were left with no explanation as to why their beautiful baby son had died.

They founded Teddy's Wish to honour their son's memory, with the aim of raising money to fund more research into SIDS, stillbirth and neonatal death and to support other grieving families. We met up with Jennifer and Chris at the ISA/ISPID conference and were once again moved by their story, which draws so many parallels with the stories we hear from other bereaved parents. Sands is proud to be working with Teddy's Wish to support research into the causes of babies' deaths.

"We decided to attend the ISA/ISPID conference in Amsterdam because it provided a rare opportunity to meet so many people who dedicate their lives to trying to solve child loss as well as to provide the essential support to parents such as ourselves."

"Our strongest memories are from meeting other bereaved parents and the strength of bond that is forged immediately through the devastating and tragic experiences we all share. We were given hope as many have gone on to have families but in equal measure inspired by the incredible passion and dedication of everyone who attended. It was great to hear the progress of so many charities,"



Chris Reid and Edward

causes, and research projects from around the globe. The update from Neal, Charlotte, and Catherine gave a great insight into the immense work Sands undertakes annually, but also the challenges that continue to remain here in the UK in tackling child loss. We hope that come 2016, Teddy's Wish will have continued to be an active supporter of the ISA/ISPID community and in the meantime that great strides can be made in reducing child loss and supporting those affected by the 'worst loss'. We know that whatever we do we will never get Edward back and that will always be incredibly difficult to cope with, but through ISA/ISPID Amsterdam we realised that we are not alone and that there is a large welcoming and supportive community."



Jennifer Reid and Edward

About Sands

Sands supports anyone affected by the death of a baby and promotes research to reduce the loss of babies' lives.

To keep up-to-date with all the latest news from Sands, please sign up to receive our regular e-newsletter by visiting our website www.uk-sands.org

If you'd like to get involved or make a donation, please contact:

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