



Spotlight on Sands

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*Tanya Coe and Daniel Curtis with
their baby son Mason James Curtis*

I write this in the wake of a period of intense media and public interest in stillbirth and neonatal death. November saw the Secretary of State for Health, Jeremy Hunt, announce his intention to reduce stillbirth, neonatal death and maternal death by half by 2030, and an important report, called for by Sands, revealed gaps in care are associated with half of all term stillbirths.

It's a sobering picture. We have known for a long time that many babies' lives could be saved by better care and this was a message that ran right through our Why17? campaign. But it is also an encouraging one, for the first step is for these failings to be acknowledged.

The second – and vitally important step – is what we do now to properly address these gaps and save babies' lives. We are now beginning to see our campaigning bear fruit: for the government to set a target for a reduction in the number of stillbirths and neonatal deaths is a major achievement.

In addition, the media interest in this issue has reached new heights; the drive to achieve significant change has never been greater. We now need to make sure the government delivers on its important goals, identify where changes can be made and lives can be saved, and that we do those things without further delay.

This edition brings you an important announcement: the launch of our new Research Fund. The Fund is designed to support research initiatives that help us better understand why babies die and identify new interventions to prevent further deaths, as well as develop innovative practice in bereavement care.

This work will underpin our overall drive to save lives and improve care, and we hope you will join us in working towards achieving this. The incredible efforts by all our supporters and fundraisers are key to why we have achieved what we have and from all of us at Sands we'd like to say a heartfelt thank you.

Judith Abela

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Judith Abela
Acting Chief Executive, Sands

Confidential Enquiry into stillbirths at term

The MBRRACE-UK collaboration, which includes Sands, has reported its findings from the Confidential Enquiry into babies stillborn at the end of a full-term pregnancy (MBRRACE stands for Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries).

Panels of experts carefully reviewed the clinical notes of 85 women and their stillborn babies, selected at random from all the normally formed babies who died late in pregnancy in 2013 in the UK. The aim of the Confidential Enquiries is to identify areas where care can be improved.

The expert panels found three common 'themes' in the antenatal care of the women whose babies were stillborn.

1: Women at high risk of developing diabetes during pregnancy did not have the tests to show that diabetes was developing. If it isn't diagnosed and managed, gestational diabetes (the type that develops during pregnancy) can increase the risk of stillbirth or health problems.

Around half of the women whose clinical notes were examined were at increased risk of developing diabetes, but two-thirds of these women were not offered testing.

2: Women did not have the size of their pregnancy bump measured and recorded properly, so it was not possible to tell that the baby's growth had slowed down – a sign that a baby is in trouble.

In nearly two-thirds of pregnancies, national guidelines for measuring and recording symphysial-fundal height were not followed.

3: Women who felt their baby's movements had changed did not receive the right care. A change in a baby's movements can signal that a baby is poorly, and women are strongly encouraged to contact their maternity unit if they think their baby's movements have changed.

Half of the women had contacted their maternity units to say they were worried about a change in movements but, for half of these women, opportunities were missed that could have potentially saved the baby.

For one-third of babies, the notes didn't show whether the parents had been offered a post mortem. And for three-quarters of the babies' deaths, the notes did not show whether a local review had been carried out to see what had happened and whether changes were necessary.

Sands has long campaigned for good-quality local reviews of care, as we believe that these can identify areas where maternity services can improve and, ultimately, reduce the likelihood of babies dying for similar reasons.

This Confidential Enquiry highlights important messages for maternity services and also for women:

- ▶ **Know the risk factors for gestational diabetes and have the right tests at the right time**
- ▶ **Make sure the bump is measured and plotted on a graph at every antenatal check after 24 weeks**
- ▶ **Have a full antenatal check if the baby's movements changed after 26 weeks**

Sands will be reinforcing these messages in all its Research and Prevention work.



Help us build a new Sands Research Fund

Sometimes people think that babies are stillborn because the baby has not developed properly and so could not live. But this is not the case for most stillbirths.

Sands supports research to help answer the questions that surround stillbirth and neonatal death. Our aim is to reduce the numbers of babies' deaths in the UK. Sands has invested more than £580k in high-quality medical research over the past 7 years at institutions including the University of Cambridge, the University of Edinburgh and Manchester University.

In 2016-17 we will build on this solid base by launching a new Research Fund and will seek to raise £300,000 a year. We will invite high calibre UK research institutions to apply for project funding.

We aim to reduce the number of babies dying by funding research that achieves the following:

- ▶ Increases our understanding of the causes of stillbirth and neonatal death
- ▶ Identifies pregnancies at 'high risk' of stillbirth and neonatal death and improves interventions to manage those pregnancies
- ▶ Defines good bereavement care

Applications to the Research Fund will go through a rigorous selection process, the criteria for which will be published on our website in advance of the fund's launch in 2016-17.

A timetable will also be published nearer the time. Priority will be given to applications that demonstrate potential to generate robust evidence that can lead to changes

in clinical practice and where appropriate we will prioritise research where most deaths might be prevented.

For the Sands Research Fund to be a success and help prevent babies dying we will need your help. Visit our website for fundraising inspiration.



Scott Ward and his son Jasper James Henry Ward

Review of maternity services

Simon Stevens, Chief Executive of NHS England, announced a major review of maternity services in England in March this year. With Baroness Julia Cumberlege as Chair, the Review is covering:

- ▶ Models of care in the antenatal, intrapartum and postnatal periods, looking at safety and choice
- ▶ The options available to women and how to balance personal preferences with safety
- ▶ Professional culture and accountability
- ▶ How best to use a range of existing and new levers and incentives (rewards and penalties) across the system to ensure that new systems are adopted

Sands' Research and Prevention Lead, Janet Scott, joined the Review Panel in September following the resignation of campaigner James Titcombe OBE, whose son Joshua died 9 days after his birth at Furness General Hospital.

Following concerns voiced by both James and Janet about ensuring the views of bereaved parents are heard as part of the Review's public consultation, Sands and the charity Bliss were tasked with organising two consultation meetings, one in Manchester and one in London, for bereaved parents to share their views on maternity services.

For those who were unable to attend these events, a survey was also

designed specifically for this group of parents to run alongside the Review's main survey.

"While maternity services do need to be reviewed and women's choice is of great importance, it's vital to appreciate that no one expects their baby to die before or shortly after birth, and the views of people who have reflected on their care after the death of their baby deserve thoughtful consideration." Janet Scott, Research and Prevention Lead.

The Review is scheduled to report early in 2016. The Scottish Government has also announced a "refresh" of its approach to maternity and neonatal services in light of the latest evidence and best practice.

New Bereavement Care Network

Sands has launched the new Bereavement Care Network in collaboration with the RCM (Royal College of Midwives), ARC (antenatal Results & Choices) and Child Bereavement UK. It is a free online resource for health care professionals working in or interested in bereavement care. It was launched at the joint 'Uncertainty and Loss' conference in September and already has over 700 registered users.

Go to <http://bereavement-network.rcm.org.uk/> to register.



Scottish Bereavement Care Awards

The Scottish Bereavement Care Awards launched at the 2015 Stillbirth and Bereavement Care conference in Edinburgh in June with the aim of supporting improvements in bereavement care provided to families who experience the death of a baby during pregnancy, birth or the postnatal period in Scotland.

Sands' Improving Bereavement Care Manager Cheryl Titherly was on the adjudicating panel alongside Mary Ross-Davie from NES (NHS Education for Scotland) and Emma Curren from RCM Scotland.

They assessed nine applications and funding of £5,000 each has been awarded to three health boards in Greater Glasgow and Clyde, Shetland and Borders.

The three winning bids are from areas with a range of challenges including rurality, isolation and a high-risk population. The bids awarded were also from three different sized units, each wanting to address different gaps in care identified by the applicants.

Upcoming bereavement care training workshops

- ▶ 24 February 2016, Cardiff (specifically for Doulas)
- ▶ 3 May 2016, Newcastle
- ▶ 10 June 2016, Cardiff
- ▶ 23 September 2016, Birmingham
- ▶ 14 October 2016, London

More dates will be added. Visit our website for details and to register.

Baby Loss Awareness Week highlights

Thank you to everyone for supporting this year's Baby Loss Awareness Week and helping to make it a huge success. Here are a few highlights:

- ▶ We worked with 14 baby charities to increase our reach and deliver a united message of support to bereaved parents and their friends and families across the UK
- ▶ £6,000 was raised through our Text 2 Donate campaign and a further £1,300 was raised by one of our corporate partners, Artemis Investment Management
- ▶ We sold over 8,000 Baby Loss Awareness pins and more than 600 'Wave of Light' tea lights
- ▶ We used #waveoflight to promote a digital 'Wave of Light' at 7pm on 15 October. #waveoflight trended on Twitter in the UK and our posts were wildly successful on Facebook, reaching over 10 million users!
- ▶ We received a wide range of media coverage including coverage in: New! Magazine, New Baby, Mums in the Know and Brit Mums

Fundraising in the workplace

At Sands, we want to live in a world where fewer babies die. We desperately need your help to help us build a new Research Fund to support essential research into stillbirth and neonatal death.

We need to raise at least £300,000 a year to support this chronically underfunded area of research.

We are asking companies far and wide to join us. From nominating us as your company's Charity of the Year to organising exciting fundraising events with colleagues, we'd love you to get involved.

If you think your company would be interested in making an incredible difference then get in touch!

We can provide lots of inspiration and support to get everyone motivated behind the Sands cause.

Contact us by phoning 0203 598 4915 or emailing fundraising@uk-sands.org

Case study: One fundraiser's story

At Sands we rely on the generosity of fundraisers and supporters to continue our vital work. Our dedicated fundraising team is there to support and motivate every step of the way. Each fundraiser's motivation and experience is unique. Here's Tom's story...

Tom Venner started fundraising for Sands following the stillbirth of his friends' baby daughter Milly in October 2014. He witnessed the support that Sands gave his friends and decided to fundraise in part to say thank you and help raise awareness of the work Sands does, but also because he now understood first hand the importance of working to prevent more babies dying unnecessarily.

Tom ran 333.05 miles (Milly's date of birth in inches, converted into miles) over 25 events between 1 March and 31 October 2015. The challenge included 17 Half Marathons and an Ultra Marathon between London and Cambridge and a number of other smaller running events.

"My fundraising has allowed me to support my friends, which I hope has helped to focus them on the future."

"Sands has been a huge support to my fundraising. They have shown genuine interest, kept in regular contact, generated additional awareness to my fundraising, supported me with event entries and best of all, been on the side of the road, in the sunshine, wind and rain cheering me on. Because of this I plan to continue to fundraise for Sands"

To date Tom has raised a fantastic £4250 – thank you Tom.



Tom Venner (right) with Milly's Dad Simon Philpott

Want to get involved?

Here are some dates for your diary...

- ▶ 13 March 2016 Adidas Silverstone Half Marathon
- ▶ 20 - 24 April 2016 London to Paris Cycle
- ▶ 24 April 2016 Virgin Money London Marathon
- ▶ 15 May 2016 DiFC Super Hero Run
- ▶ 22 May 2016 Great Manchester Run
- ▶ 28 - 29 May 2016 Edinburgh Marathon Festival
- ▶ 30 May 2016 Bupa London 10,000
- ▶ 1 - 30 June 2016 Sands Awareness Month

Parent perspective

Shavon Perkins was 10 days overdue when her son Joseph Little was stillborn. She'd had no issues during her pregnancy and when her baby's movements changed towards the end of her pregnancy she hadn't been overly concerned.

"Three days after my due date I saw a consultant because I was overdue. She asked me about my baby's movements and I said that they had changed. They were less frequent, less distinct. She dismissed it; she said it was because I was having a big baby and it was engaged in the birth canal ready to be born."

Devastatingly for Shavon that wasn't true. At 10 days overdue, when Shavon went back to the hospital worried about a complete lack of movement, a scan revealed her baby had died. She eventually went into labour spontaneously and gave birth to a small but perfectly formed baby boy named Joseph.

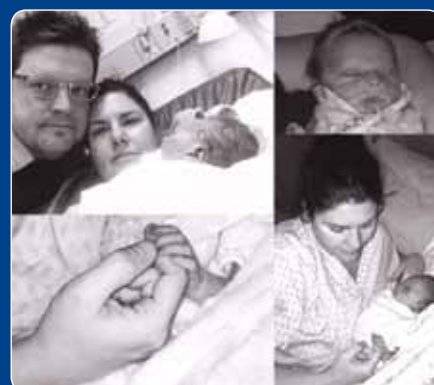
"All the agony and beauty and love and pain was rolled into this perfect but silent baby."

It was later found that Joseph's death could have been prevented.

"A post mortem revealed that I have Factor V Leiden, a common and treatable genetic clotting disorder. It's terrible to think that I might have been prescribed something as simple as an aspirin and my son would be here."

"An audit of my care found that I'd seen a higher than usual turn around of staff – I didn't see the same midwife twice."

"It was noted in my records that Joseph was measuring small but they didn't know when his growth had tailed off because it wasn't plotted on any growth chart, and at some visits his growth, or my fundal height measurements, wasn't recorded at all. He suffered from intrauterine growth restriction (IUGR) but we found out much too late to help him."



Shavon and Richard with their son Joseph

Tracking growth and monitoring a baby's movements can significantly reduce stillbirth rates. Since Joseph's death, the hospital that looked after Shavon has changed its pregnancy notes to include growth charts.

Shavon and her family have fundraised to train other hospitals to use the GAP (Growth Assessment Protocol) measuring system that more accurately detects growth rates. They have also fundraised and established a dedicated bereavement suite at their local hospital.

About Sands

Sands supports anyone affected by the death of a baby, works to improve bereavement care, and promotes vital research to save 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

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

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If you'd like support or want to find a local Sands group please contact us or visit our website:

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