

Spotlight

on Sands

2018



**#FindingTheWords: Sands
Awareness Month campaign 18**


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#FindingTheWords: our awareness- raising campaign


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Credit: Chris Heale



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Inspiring fundraisers

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Stories and poems

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Make a donation
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Get involved
sands.org.uk/
get-involved

Support for you

t: 0808 164 3332
e: helpline@sands.org.uk
w: sands.org.uk

Sands online community
www.sands.community

Sands bereavement support app
sands.org.uk/app

Feedback

We'd love to hear your comments
surveymonkey.co.uk/r/spotlightonsands

Stay up to date with our e-news

Get regular information about our work and
recent news at sands.org.uk/newsletter



Follow us on social media

Dear Friends

Welcome to the new edition of Spotlight on Sands

In this issue we will be sharing with you some of the amazing work that is being done by all the wonderful people involved with Sands in so many different ways.

We have been taking positive steps to break the taboo surrounding baby loss with our #FindingTheWords campaign (p.18) which we ran throughout June, focussing particularly on helping employers, family and friends to talk to bereaved parents about their babies.

We have also continued to find new ways to reach as many bereaved parents and healthcare professionals as possible, working to expand the reach of the National Bereavement Care Pathway (p.13) and launching our new bereavement support app (p.26) that provides information and guidance in a format that is quick and easy to access.

Alongside these achievements, Sands freephone helpline has been accredited by the Helplines Partnership (p.7), evidence of our commitment to providing a high quality helpline service to all those who need it.

And of course this year we celebrate Sands' 40th anniversary (p.8) – looking back and celebrating how much has been achieved since Bel Mooney and Hazelanne Lewis founded the charity in 1978 after their own experiences following the stillbirths of their babies.



With help and input from many of you, we have put together the virtual 40th anniversary timeline, and the breadth and scope of what has been achieved is a testament to the wonderful work of all those who have been involved in Sands over the years.

As well as celebrating how much has been achieved, it has also been a good moment to look forward and acknowledge that there is still more to do. By working together I know we will continue to reduce the number of babies dying, and to improve the care and support received by all those affected by the death of a baby.

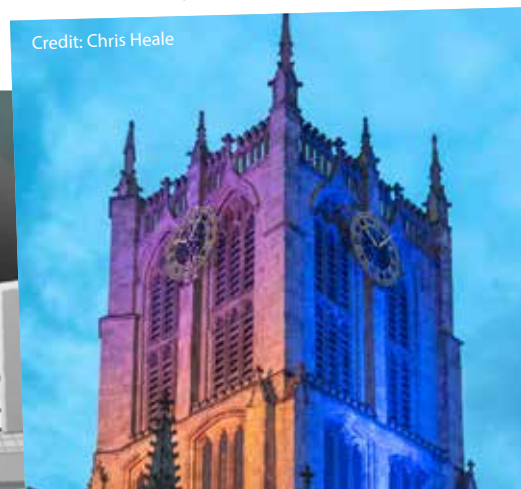
I am immensely proud to be involved with such an amazing organisation, and am enormously grateful to all of you for your incredible work and support – thank you!

Dr Clea Harmer

Chief Executive, Sands

▼ From left to right: All kinds of fundraising for Sands continued throughout our 40th year. A still from our #FindingTheWords animation. Hull Minster lit up to celebrate our anniversary.

Credit: Chris Heale



The year ahead

Key dates for your diary

2018



17 November

Sands' 40th Anniversary Conference, Glasgow

Aimed at trustees, members, staff, volunteers, befrienders, bereaved parents, supporters and donors, the conference seeks to provide an opportunity for the whole organisation to come together, celebrate what has been achieved by Sands over the last 40 years and commit to what more needs to be done to make our vision a reality.

The theme for 2018 is Past, Present and Future, to reflect the achievements of all those who have worked with us over the years to support anyone affected by the death of a baby, improve bereavement care and fund research to reduce the number of babies dying.

sands.org.uk/conference



7 December Lights of Love

Our annual Lights of Love services are held at venues across the UK and are organised by our dedicated volunteers. The services are

family-friendly evenings of traditional carols, readings, and musical performances.

sands.org.uk/lightsofloves

2019

1–30 June

Sands Awareness Month

In the UK, 15 babies die before, during or shortly after birth every day. Every June, we work hard to raise awareness of issues relating to stillbirth and neonatal death.

sands.org.uk/sandsawarenessmonth



15 June

Sands Garden Day and Remembrance Event, National Memorial Arboretum, Staffordshire

This annual event offers anyone affected by the death of a baby the opportunity to meet with others in a peaceful setting. The service is followed by a short dedication in the Sands Garden.

sands.org.uk/gardenday



9–15 October

Baby Loss Awareness Week

The annual awareness week is a collaboration between over 60 charities that provides an opportunity for bereaved parents, families and friends to commemorate babies' lives and break the silence around pregnancy loss and baby death in the UK.

babyloss-awareness.org



▲ A still from our campaign animation

Sands Awareness Month sees launch of #FindingTheWords campaign

In June, we launched a campaign featuring an animation showing a 'day in the life' of a bereaved parent and calling on everyone in society to help break the silence around baby loss.

We also urged employers to get in touch for advice, after a Sands survey revealed that parents struggling to cope after the death of their baby are often let down by their employer if they return to work. Only one in five bereaved parents surveyed had been offered or provided with any bereavement support by their employer, and almost half said employers did not discuss entitlements to pay and leave with them, following the death of their baby.

[Read more on page 18](#)

New bereavement support app is launched

We are always looking to improve and expand on the different ways we offer bereavement support to anyone affected by the death of a baby for as long as they need it.

We have created a brand new mobile bereavement support app for parents, family and friends, partners, grandparents and healthcare professionals where they can access information at their convenience on their smartphone.

The idea to create an app was inspired by Nicole Regan-White whose baby daughter Jessica was stillborn in 2013.

[Read more on page 27](#)

Download from your app store



Action across the UK during Baby Loss Awareness Week

In its 16th year, Baby Loss Awareness Week 2018 saw more than 60 charities collaborate to raise awareness of the key issues affecting those who have experienced pregnancy loss or baby death in the UK.



This year the coalition urged all NHS Trusts and Boards to adopt the National Bereavement Care Pathway (NBCP), a partnership led by Sands between government, charities, and the NHS, that sets out the standards for providing excellent care to anyone affected by pregnancy loss or the death of a baby.

There were many ways to get involved, including helping to turn buildings pink and blue, wearing the ribbon pin badge, spreading the word amongst friends, family and colleagues and emailing MPs and other decision makers.



Thousands of people came together to help break the silence around pregnancy and baby loss. Our most heartfelt thanks to those who got involved. We look forward to seeing even more of you taking part in #BLAW2019!

babyloss-awareness.org

Sands urges the government to help pregnant women quit smoking

Sands and the Smoking in Pregnancy Challenge Group have called for the government to take action to tackle the number of women who smoke during pregnancy. Such action has the potential to prevent harm to hundreds of babies every year.

We are calling for action by the government to reduce the rates of women who smoke during pregnancy as they are failing to meet their target. Pregnant women who smoke can visit our Safer Pregnancy website for advice on quitting at:

saferpregnancy.org.uk



New parliamentary Act to help bereaved parents

We were pleased to hear that The Parental Bereavement (Leave and Pay) Act has now become law in UK Parliament.

The Act will introduce a minimum of two weeks' leave for employees whose baby or child has died. This will include parents whose baby is stillborn or dies neonatally.

We welcome the Act and the proposals to ensure all parents, including those who experience a stillbirth or neonatal death, have a right to at least two weeks' paid leave from work in addition to their existing parental leave entitlement.

Sands helpline receives accreditation accolade

Our freephone helpline has been recognised and awarded with an accreditation by the Helplines Partnership (HLP).

The helpline was assessed and was found to show a duty of care to bereaved parents and their families, and to the staff who operate the service.

The HLP found that our helpline was at the heart of the services we provide and offers a recognised standard of care and professionalism.

We are delighted that the results of the assessment show the helpline operates within a standard of practice that bereaved parents, their families and anyone affected by the death of a baby can trust.

For the latest news and updates from Sands, visit sands.org.uk/news

Subscribe to receive our e-news sands.org.uk/newsletter

40 years of being the voice of bereaved families

In 2018, Sands turned 40! We've been busy with lots of activities to mark the occasion and honour the achievements of everyone who has worked with us to support bereaved parents and reduce the baby death rate in the UK. Read on to find out what we've been up to.

40 stories

Back in June, we asked parents, family members and friends affected by the death of a baby to share their stories and experiences of loss, including those who were bereaved long ago.

We've been overwhelmed by the amazing response, receiving many powerful stories, 40 of which we've picked to share on our website and social media. Together, these stories will continue to raise awareness of the issues surrounding stillbirth and neonatal death, and also help other bereaved parents to understand that they are not alone.

sands.org.uk/40stories

40 words

We also asked supporters for 40 words about what Sands means to them, receiving heartfelt responses in a variety of creative formats. If you'd like to share yours, please email:

findingthewords@sands.org.uk

40 years

To illustrate just how far we've come, we put together a timeline to showcase the history of Sands. Take a look at page 10 to see our key milestones, or view the virtual version online.

sands.org.uk/timeline

40th Anniversary Conference

With a theme of Past, Present and Future, Sands' 40th Anniversary Conference and AGM provides a wonderful opportunity for the whole organisation to come together in Glasgow, to celebrate what has been achieved by Sands over the last 40 years and commit to what more needs to be done to make our vision a reality.

sands.org.uk/conference



▲ Fundraising for Sands during our 40th year.

40 volunteers

Our volunteers are fantastic! We've been celebrating their efforts by highlighting 40 of them on our website and social media, with a special awards ceremony on 17 November.

sands.org.uk/40volunteers

#Sands40

Thank you to all those who have reached out to us on social media, made use of our digital toolkit and spread the word with hashtags: #Sands40 #40yearsofsupport #TeamSands #40storiesforSands

"Today would have been my little girls, Gracie, Lottie and Pippa's 10th birthday. Everyday it's hard and a struggle, without @SandsUK I don't know where I would be. So a huge thank you to all @SandsUK staff, you are amazing. x"

🐦 Donna Wilson

40th fundraising

Across the UK, many people have been holding fantastic Sands 40th anniversary and Walk a Mile in My Shoes fundraising events, sharing and celebrating memories while raising awareness and vital funds for the charity. If you'd like to organise your own event, register on our website and we'll be in touch to send posters, balloons, bunting and more.

sands.org.uk/register-your-fundraising



"Everything I do for Sands, I'm doing for my son."

Volunteer profile:
Edel Campbell, Befriender

As well as taking part in fundraising events, in her role as a befriender, Edel supports parents at Cookstown Sands.

"I am absolutely delighted to hear I have been nominated for an award. I was not expecting this at all. I first became involved with Sands 12 years ago, after we lost our first-born son Conan at two days' old (born at 28 weeks). Over the years, I have taken part in many events and organised fundraising events for the charity, and to be honest, this has kept me going. Because Conan never got the chance to do a marathon or a mud run, I did these events on his behalf. Everything I do for Sands, I'm doing for my son and it keeps his memory alive. So for me this is not my award, it's Conan's."



For more information about our 40th anniversary, visit sands.org.uk/sands40

The history of Sands

Our key milestones show just how far we've come since Sands was founded, as we've strived for a world where fewer babies die and anyone affected by the death of baby receives the best care and support for as long as they need.

1978

Bereaved mothers Bel Mooney and Hazelanne Lewis found Sands during a time when most parents are not allowed to see, hold or have a funeral for their ~~stillborn~~ babies. No photographs are taken, nor is the baby's name included on the stillbirth certificate.

1985

Sands helpline set up.

1986

Sands' first support booklet, Saying goodbye to your baby, is published.

1991

Pregnancy Loss and the Death of a Baby: Guidelines for Professionals is published for the first time.

1993

Sands introduces teardrop stickers for the hospital notes of bereaved parents.

2000

First Garden Day and Remembrance Event.

2003

First Baby Loss Awareness Week.

2006

Sands joins the International Stillbirth Alliance, a collaborative global effort to reverse stillbirth rates and improve bereavement care.

2009

Sands' Saving Babies' Lives report highlights that some babies' deaths are potentially avoidable and calls for collaborative commitment to address these.

1992

Following lobbying by Sands and other groups, the Still-Birth (Definition) Act comes into force, changing the definition of stillbirth from 28 to 24 weeks of pregnancy.

1996

First Sands Awareness Week.

2004






First Lights of Love service.

2005

Sands launches an online community to provide bereaved parents with support 24/7.

2008

Sands begins providing free memory boxes to bereaved parents and families.





“In 1975 things were very different.”

Hazelanne Lewis, co-founder of Sands

Hazelanne Lewis, psychiatric social worker and co-founder of Sands said: “When I gave birth to my stillborn baby in 1975 things were very different than they are today. My baby was taken away from me almost instantly, delivered with nurses leaning over me and they took him out of the room so I couldn't see him. The midwives made no eye contact and they instructed my husband not to discuss our baby with me.

My experience spurred me on to reach out to other bereaved parents who had been through the same ordeal and we formed a support group which became Sands. Thankfully bereavement care has changed for the better since the 1970s and we have seen the number of baby deaths reduced, but more research work needs to be carried out to reduce the number of deaths even further.”

Find out more on our virtual timeline at sands.org.uk/timeline

2010

Sands begins funding research that could help to reduce stillbirth and neonatal death.

Sands publishes the Bereavement Care Report, investigating the standard of bereavement care in maternity units across the UK.

Why17? exhibition at OXO Gallery showcases 17 photos of pregnant women affected by the death of their baby.

2012

Sands' Preventing Babies' Deaths report calls for better data and research into baby deaths, increased public awareness of stillbirth risks, better reviews and improved bereavement care.

2013

Samantha Cameron hosts a reception at 10 Downing Street in support of Sands.

2015

Sands works with EastEnders scriptwriters and actress Rakhee Thakrar whose character has a stillborn baby.

2016

Formation of the All-Party Parliamentary Group on Baby Loss brings MPs and peers together to improve care for bereaved parents and raise awareness of the issues around baby death within parliament.

2017



Launch of the National Bereavement Care Pathway.

Sands advises on a Coronation Street storyline where character Michelle Connor's baby dies at 23 weeks.

saferpregnancy.org.uk goes live.

Sands is able to make memory boxes available to hospitals free of charge.

Sands' #15babiesaday initiative highlights that 15 babies die before, during or shortly after birth in the UK every single day.



Working with professionals to improve bereavement care

The care parents receive when their baby dies can have a huge effect on their physical and mental health, in both the short and long term. While no level of care can remove the grief that parents feel, good care can make a devastating experience feel more manageable, while poor-quality or insensitively-delivered care can compound and exacerbate pain.

As the quality of bereavement care that parents receive varies across the country, Sands offers specialist, RCM-accredited training to healthcare professionals, to ensure that a minimum standard of care is offered. From 2017 to 2018, Sands trained more than 2,600 professionals, including midwives, doulas, health visitors, interpreters and multi-disciplinary teams. Sands training courses get consistently positive feedback and most participants report feeling more confident about communicating sensitively with bereaved parents.

“
The course was delivered professionally but with so much heart. It has truly made an impression upon me and I intend to take what I have learnt forward into practice.
”

Workshop participant

During our workshops, we provide an opportunity for participants to hear directly from a bereaved parent, looking at the wider impacts of a baby’s death. We explore how to break bad news sensitively and how to provide empathic care in the aftermath. Finally, we cover self-care strategies. It is important to acknowledge the impact of providing bereavement care on the professionals, and to ensure that they are supported.

Healthcare professionals can book onto a workshop by emailing training.professionals@sands.org.uk

Find out more at sands.org.uk/our-work/working-professionals

Sands Guidelines for Professionals

Sands Guidelines for Professionals have formed the basis of Sands’ work with healthcare staff for many years. They have been recognised as a leading resource for those working with bereaved families since they were first published in 1991, helping to drive forward improvements in the delivery of bereavement care across the UK.

Now in their fourth edition, the Guidelines bring together research evidence, best practice and the experiences of bereaved families to provide detailed guidance on how to deliver effective, parent-led bereavement care through early and late miscarriage, termination for fetal anomaly, stillbirth and neonatal death.

The Guidelines combine decades of work by Sands with advice and feedback from more than 60 experts, and have been endorsed by 22 leading organisations working with bereaved families.

Since the fourth edition of the Guidelines was published in 2016, nearly 1,150 copies have been sold to healthcare professionals, and copies are now available in most UK maternity and neonatal units. This unique collaboration between bereaved families and healthcare professionals helps to ensure that parents receive personalised, empathic care at the time they need it most.

sands.org.uk/guidelines

Success via the National Bereavement Care Pathway

At Sands, we’re proud to be leading on the National Bereavement Care Pathway (NBCP), a project that aims to ensure all bereaved parents are offered equal, high-quality, individualised, safe and sensitive care in any experience of pregnancy or baby loss.

Working with parents, charity partners, Royal Colleges and other key stakeholders, we helped to launch the pathway in October 2017 at 11 sites across England. This generated great momentum and excitement, to the extent that we were oversubscribed with interest. Ultimately, a further 21 Trusts in England joined us for the second wave of the project in April 2018, trebling the number of pathway sites to 32.

We continue to be delighted by the support we have received from the Scottish Government, providing funding to initiate the project in Scotland and create a

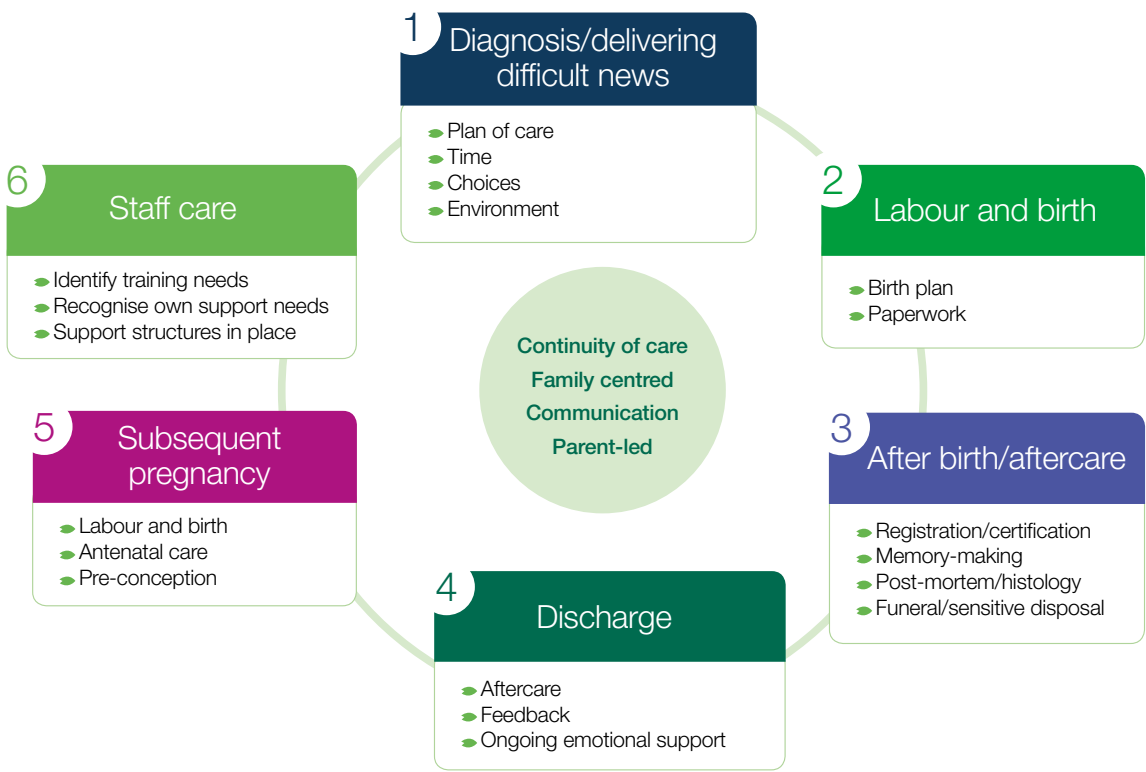
specialist post at Sands. This fantastic development will enable us to work closely with partner charities and other organisations to develop, implement and embed the pathway in Scotland over the next two years. We hope to reach the rest of the UK by March 2020.

Together with the Parent Advisory Group and independent evaluators Fiveways, the pathway project team carried out a very successful evaluation of the NBCP with healthcare professionals and bereaved parents.

We are always struck by the generosity of those who share their time and experiences with us, to ensure that the documents we produce are based on evidence and are appropriate for those who have suffered a loss.

Thank you to everyone who has helped so far.

The NBCP helps professionals to support families in their bereavement through six key stages:



 To get involved as a parent or a professional, please contact Marc Harder, Project Lead, at marc.harder@sands.org.uk or visit nbcpathway.org.uk

The latest in research and prevention

Learning from baby deaths with a new review tool

Sands has championed the need for better hospital reviews when a baby dies since 2012. Too often after the death of a baby, families go home without the fullest possible picture of events around their baby's death. This year has seen the launch of an important new way to learn lessons and improve future care.

The Perinatal Mortality Review Tool (PMRT) is an online tool to support healthcare staff in reviewing a baby's death. Free to use in England, Scotland and Wales, the tool provides a guided format for hospitals to look at all aspects of care, from antenatal care right through to bereavement care. Where necessary, the tool will generate issues around lesson learning where future care could be improved.

Sands is helping to develop the PMRT, providing guidelines around what good quality bereavement care should look like and ensuring parents' voices are included in reviews.

For more information go to sands.org.uk/pmrt

From research to advice for pregnant women

Sands Research Fund has awarded almost £1 million in grants since 2010. These have examined a range of questions including: how to use scans to predict babies at risk in the last trimester of pregnancy; which aspects of a post mortem yield the most useful information; and how to use fetal movement monitoring to reduce stillbirths. We recently co-funded The Midlands and North of England Stillbirth Study, which estimates that if all pregnant women in the UK went to sleep on their side in the last three months of pregnancy, about 130 deaths a year might be avoided.

Our pregnancy website carries this advice for pregnant women saferpregnancy.org.uk

Reducing stillbirth rates

The Saving Babies' Lives Care Bundle was introduced by NHS England in 2013, in response to Sands and others highlighting the UK's unacceptably high stillbirth rates. The care bundle is a trigger for helping units implement current best practice.



It focuses on four key elements of maternity care: reducing smoking in pregnancy; assessing fetal growth restriction; raising awareness of reduced fetal movements; and effective fetal monitoring in labour.

Five years on, Sands has supported work evaluating how effective the care bundle has been in reducing stillbirths. A team led by researchers at Manchester University analysed data from almost half a million pregnancies in 19 Trusts. They found that in those units where the care bundle was implemented, stillbirths fell by 20%. Though it isn't certain the fall was due solely to the care bundle, the improvement is extremely welcome news.

“

In those units where the care bundle was implemented, stillbirths fell by 20%

”

NHS England is currently working on a Care Bundle 2, which will add new elements and include public health messages about stillbirth risk, drafted by Sands.

Sands supports research to help answer the questions that surround stillbirth and neonatal death, funding some studies directly and supporting others by helping to recruit participants and acting as a co-applicant on requests for funding.

Read more about the care bundle evaluation at sands.org.uk/safercare



For more information about our research and prevention work, visit sands.org.uk/our-work/research

Updates from across the networks

Our countrywide networks with over 100 local support Groups, usually run by bereaved parents and family members, offer a chance to meet others, gain support and share your experience. Read on for recent highlights from Sands Groups.



A visit from Princess Anne



Volunteers from Dumfries and Galloway Sands showed Princess Anne around the bereavement suite when she opened the new Royal Infirmary on 12 July. Princess

Anne's daughter, Zara Phillips, has spoken about the late miscarriage she suffered in 2016.

Alison Hall and Alison Carruthers spoke to the Princess about the importance of a bereavement suite. Alison Hall said: "Ali talked about her own experience and the support offered by Sands."

She said meeting the Princess was "...the kind of experience that really makes everything we do worthwhile."

Northern Irish golf challenge

Four friends attempted an epic golf challenge in Northern Ireland in June 2018: to play four rounds of golf in one day. Kevin Gallagher and his three friends had an early 5.30 am tee off. After 13 and a half hours of golf, they completed their challenge to raise awareness and funds for Sands.

Kevin said: "You won't believe it, but the match came to a draw after 72 holes! There was loads of people out watching. It was hard going, but was 100% worth it for an amazing cause."

Volunteer is Pride of Britain nominee

Dawne Braine of Hastings and East Sussex Sands has been recognised for her fundraising. Dawne has been fundraising for the Conquest Hospital, and supporting bereaved parents via their Sands' befriending. Dawn said: "Supporting bereaved families and fundraising are my way of keeping my George walking beside me every day. I made him a promise before he passed away that he would be remembered always, so this isn't my award, it's George's."

Newport's butterfly garden



A new butterfly garden opened in July at Royal Gwent Hospital, Newport, thanks to fundraising by Cardiff & Newport Sands, along with the chaplaincy team and the Rotary Club.

Heatherjane Coombs, Sands Welsh Network Coordinator, said, "The garden is a safe haven outside antenatal for people to sit and think following bad news."

The garden hosts animal statues with a postbox, enabling families to post letters to their loved ones. At the opening, families donated bulbs and seeds, and bubbles were released in memory of their babies.

Find a Group at sands.org.uk/groups or subscribe for Group news at sands.org.uk/newsfromgroups

Art as therapy with a Sands befriender

by Tommy Ferguson

I sadly got involved with Sands after the death of my son Joshua in 2009. Myself and my wife Leslie got a lot of support from Belfast Sands and wanted to give something back.

When I first heard of art as therapy I thought it was a bit cheesy and not quite for me. I'm no good at art, I don't even like drawing that much and well – therapy?! Chatting to the other bereaved parents there, we were almost all of one mind – this'll be awful but let's give it a go. The facilitators got us all on seats in a circle with dozens of random images laid out on the floor between us. The idea was that you had a good look at all the images and chose one that attracted you. Then you got a piece of paper and whatever materials you wanted, and created something inspired by your image.

There were no specific instructions on how to do it and in fact the process of creating was the important part of the morning. I nervously watched other people create beautiful pictures while I stared at a blank page. One of the facilitators saw this and asked me a few questions, then pop! A whole image came into my mind and I was done in two minutes!

Because I had finished early, I took the opportunity to walk around the hall and introduce myself. People hugged me spontaneously or cried as they told me their story and there was even laughter and real joy as I heard why they had created what they did. We then gathered into groups to discuss our creations and these reactions were even more powerful – I found myself in tears and the support I got from the group was inspiring.

This made me want to share the experience with other bereaved parents. I hosted an art as therapy session at Belfast Sands where I'm a befriender and the group went through all the initial emotions I did – and came out the other end amazed.

One mother said it was the most powerful thing her partner had done since the death of their baby – it really opened her eyes to how he felt. Others took great comfort in being able to express themselves in ways they couldn't verbally. Most of these were in terms of happiness – it somehow didn't feel right to be happy given the death of their baby, but they could express their joy in artwork. After all, our babies are still our children. Even if they are not here, we can still be happy.



"People hugged me spontaneously or cried as they told me their story."

Sands befrienders play a vital role in offering support to bereaved families throughout the UK. We are hugely grateful to the many volunteers on whom our service relies. Find out more at sands.org.uk/befrienders

#FindingTheWords

Sands Awareness Month campaign

For Sands Awareness Month in June 2018, we launched the #FindingTheWords campaign to help break the silence around stillbirth and neonatal death.

We wanted to help everyone start a conversation about baby loss with anyone they knew whose baby had died, however long ago. We also urged employers to get involved and support parents returning to work after the death of a baby.

At the heart of the #FindingTheWords campaign was an animation showing a 'day in the life' of a bereaved parent struggling to cope.

A campaign hub on the Sands website included the animation, advice on starting a conversation about baby loss, information for employers, and other ways for people to get involved, such as social media banners and suggested posts, and signing up to fundraise through Walk A Mile In My Shoes.

Dr Clea Harmer, Sands Chief Executive, was interviewed by The Victoria Derbyshire Programme on BBC2 and Sky TV News spoke to bereaved parent Amanda Wood about the support she was offered when she returned to work following the death of her daughter, Layla.

During June, we also shared stories of bereaved parents and families in a dedicated blog series.



“
The animation was seen by more than 380,000 people during June and the campaign web pages were viewed more than 19,000 times!
”

Sands' 40th anniversary was highlighted throughout the campaign and more than 50 local Sands Groups ran fundraising and awareness events. Hull and East Yorkshire Sands worked with their local community to turn their city orange and blue. Eszti Pontone, Group Treasurer, said: "We've been so touched by the businesses who have taken this on because it is still a taboo subject."

Find out more at
sands.org.uk/findingthewords

► From left to right: Sands bunting lined Humber Street in Hull. Queen Victoria Square in Hull turned blue and orange. Groups were busy fundraising throughout June.



Sharing the words of bereaved families

During the planning for the campaign we ran a survey to find out more about the experience of parents and other family members returning to work after the death of a baby, and more than 2,700 bereaved parents, grandparents, and other family members took part.

Almost all parents who responded (95%) had shared the happy news of their pregnancy with colleagues, but after returning to work two in five said no one talked to them about their loss.

Only one in five parents surveyed said they had been offered or provided with any bereavement support by their employer, and almost half said employers did not discuss entitlements to pay and leave with them, following the death of their baby. Many mentioned the importance of other people feeling able to talk about the death of their baby.

"At first my colleagues never said a word about my baby, although quite a few of them, including my manager, attended the funeral, which was very kind and very supportive. Over the first few weeks, gradually people did broach the subject with me. I wish someone had said to them, it's okay to talk to me about the baby."

Overall, the campaign was very well received and many people commented on social media to let us know it had made a real difference:

"I started a conversation with a friend of my in-laws yesterday about the baby boy she lost 45 years ago. I don't know her very well, but I decided to be brave! It was nice to be able to use his name and ask her about him, and I hope she found it cathartic. She certainly lit up when she talked about him."

"We must break the silence around baby loss."

Bel Mooney, co-founder of Sands



Author, journalist and co-founder of Sands, Bel Mooney, said: "The short but oh-so-powerful animation brought tears of recognition to my eyes, nearly 43 years later. The loss of a baby is with you forever, and I can still recall people turning

away awkwardly, not knowing what to say. Yet words of understanding and compassion are not really hard to find – and I believe that friends and colleagues can be 'taught' how to respond to this shockingly common bereavement.

"We must break the silence around baby loss. And that reaching-out in simple human sympathy can start in the workplace, if employers recognise the importance of what has happened and colleagues realise that saying quietly, 'I'm so sorry to hear what happened' is not, in fact, very hard at all."



Share your story at
sands.org.uk/shareyourstory

Whatever your passion, there's something for everyone

The death of a baby before, during or shortly after birth is a devastating experience with lifelong consequences for the whole family. Each year, Sands works to support thousands of bereaved families and improve the care they receive, as well as fund vital research to prevent more families suffering the loss of their precious baby.

Our work is totally dependent on donations and would not be possible without the generosity of our amazing supporters. There are hundreds of enjoyable ways to get involved, from fun runs to marathons, sponsored bakes to attempts at record breaking – the sky's the limit. Use your imagination and create your own challenge; we'd love to hear from you!

Remember that whatever you choose, it's usually best to select something you like doing. That way, not only will you be helping us but you'll be enjoying yourself too.

By fundraising for Sands, you will help us to provide essential support for anyone affected by the death of a baby, and aid our work to reduce death rate in the UK.

Be sure to visit [sands.org.uk/get-involved](https://www.sands.org.uk/get-involved), to see upcoming fundraising events and campaigns, find out about volunteering, get ideas for fundraising at work, sign up for your Sands fundraising pack and much more.

However you choose to fundraise for Sands, we'll be there to support you every step of the way!



“Thank you very much for the fundraising pack, it's such a great support to get my fundraising up and running.”

Caitriona McGloin, Sands Supporter

Bake for Sands

If you love baking, there are lots of ways you can turn your showstopping skills into raising funds. Download our Bake for Sands pack from [sands.org.uk/bake](https://www.sands.org.uk/bake) to get started!

Run, jog or plod for Sands

Whether you're a cyclist, a runner, a jogger or a plodder, visit the events section of our website to find loads of fundraising events to take part in. If you can't see what you're looking for, please do get in touch with our friendly fundraising team at fundraising@sands.org.uk or call 020 3897 6092 and we'll see what we can do to help.



Runs

19 May Great Manchester Run and Half Marathon

The greatest running event in Manchester, known for its buzzing atmosphere, incredible supporters and booming Manchester anthems!

25–26 May Edinburgh Marathon Festival

Offering stunning views and an unforgettable running experience, the Edinburgh Marathon Festival is Scotland's largest running event.

27 May Vitality 10,000

A flat, fast 10k through London with an iconic route past Nelson's Column, St Paul's Cathedral, Big Ben and many more!

29 September Berlin Marathon

A marathon party lasting 26 miles, with 1 million spectators lining the course through the German capital.

6 October Cardiff Half Marathon

One of the UK's biggest and best road races around Wales' stunning capital city.

13 October Great Birmingham Run

Hit the streets to your favourite music for an electric party atmosphere that will keep you going from start to finish.

Cycles and challenges

April – September Tough Mudder

A series of hardcore 10–12 mile obstacle race mud runs to challenge the toughest of the tough throughout the UK.

6 July and 31 August TrekFest

Challenge yourself to TrekFest 2019! Trek 25k or 50k across the Peak District or the Brecon Beacons.

4 August Prudential RideLondon 100

A spectacular 100-mile ride and the world's greatest cycling festival!

15 September

London to Brighton Cycle

An event for cyclists of all experiences and levels – a scenic 54-mile ride from Clapham Common to Brighton seafront.

Join Team Sands...

...and take part in amazing challenges to help raise vital funds and awareness.

Whether it's falling through the sky at 120mph, jogging your first 5k, running a marathon, climbing a mountain or conquering an epic trek, we'd love you to join us and get involved. Whatever you're interested in, we've got the challenge for you!

Find out more at [sands.org.uk/get-involved](https://www.sands.org.uk/get-involved)



Taking on the Big Fun Run in Leeds

Fun runs

12 May Superhero Run

Grab your cape and join thousands of fellow runners to become a Sands superhero.

July – October Big Fun Run Series

With 18 locations throughout the UK, you can take part in a 5k near you and run for fitness or fun... just run for Sands!

2 December* Santa Run

Join 2,000 Father Christmases and be a Sands Santa in this 5k or 10k festive fun run.

*Subject to change

Running a marathon for baby Minnie

Together with his younger brother Ollie, our superstar supporter Ben Quiney raised over £8,000 for Sands, running the London Marathon in memory of Ollie's baby daughter, Minnie. Here, Ben tells us about his perfect niece and deciding to take on the challenge of a lifetime to help others affected by the death of a baby.

by Ben Quiney

Back in October 2014, my awesome younger brother Ollie and his amazing wife Amy lost their newborn daughter Minnie at one day old. This was due to an undetected lung infection, which was not identified until immediately after she was born.

Minnie was absolutely beautiful, perfect in every way. I will personally cherish forever the few short moments I had cuddling and holding her. She was and is an angel.

Losing Minnie was an extremely traumatic and upsetting experience, and one that Ollie, Amy and both of their families will never get over or truly understand.

Moments afterwards, Sands kindly provided us with a memory box. We put the name tags and the usual keepsakes associated with a new baby into this box. Unfortunately, this was all Ollie and Amy walked away from the hospital with that day. It's a vivid and raw memory I will never forget.

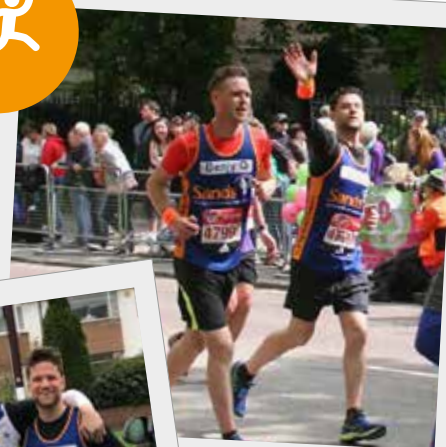
In May 2016, Ollie and Amy had their third child, Arlo. Just like their first child Alfie and Minnie, Arlo is beautiful and awesome. As soon as Arlo was born, we started discussing what we could do to support Sands and the people who had helped Ollie and Amy over the previous years. Finally, the time felt right to do something for this amazing charity.

Sands had supported Ollie and Amy in so many ways. They'd always been there and we really wanted to give back to this wonderful charity, so that Sands could continue to help other families who might have a similar harrowing experience. We were keen to raise as much money as we could – we thought it was the best way to say thank you.

We weren't aiming for a time in the London Marathon, we definitely weren't going to win; we just wanted to enjoy it (if at all possible) and finish it together, thinking about our beautiful little girl, Minnie.

The marathon was an emotional and brilliant day in so many ways. We can't think of a better way to have done something really positive for Minnie.

Thanks for reading our story and thanks to all of you who donated to support this amazing charity.



ollie and Ben

The Roses take on RideLondon

A team of friends and family called The Roses took part in RideLondon 2018 to raise awareness and funds in aid of Sands.

RideLondon is the world's greatest festival of cycling, with thousands of cyclists participating over the two-day event.

The Roses team members Sarah and David Abbott's daughter Lizzie was given the devastating news that her baby daughter, Ella, had died at 34 weeks gestation.

Sands supported the family by providing Lizzie with a memory box, which helped them to create precious memories.

"My husband, David, and I decided that we needed to do something to raise awareness for the work of Sands." Sarah explained, "They have been there for us in our very darkest hours and for as long as we have needed them to be."

The Roses joined more than 100,000 cyclists to take part in RideLondon and their challenge saw them cycle through London and Surrey on a route similar to that of the London 2012 Olympics road cycling races.

The Roses are great fundraisers and ambassadors for Sands. They have already raised an incredible £15,000 in memory of Ella, they were interviewed about their challenge on BBC Radio Surrey, and were featured in RideLondon – The Riders' Stories.

Sarah said, "I never thought in a million years that I could do it when I first approached Sands, initially for a place in the 46 mile ride, never 100 miles... We have met some amazing people during our fundraising, who talked to us about their babies – some from many years ago, very humbling. Keep up your amazing work! If the money we raised prevents one family from going through what we have been through, it will have been worth it."



The Roses #TeamSands



Feeling inspired?

Find out how you can get involved at

[sands.org.uk/events](https://www.sands.org.uk/events)

Company fundraising

Each year, we work with a variety of companies who chose Sands as their charity of the year. Often we are nominated by an employee who has recently returned to work following the death of their baby or by an employee who knows someone who has been supported by Sands.

Alliance Pharmaceuticals chose Sands as their charity of the year after staff nominated and voted for Sands. Alliance Pharmaceuticals originally had a fundraising target of £12,500 but, after our Corporate Fundraiser visited their offices to give a presentation about our work, they increased the target to £15,000 to highlight that every year in the UK, 15 babies die shortly before, during or soon after birth.

To help them achieve this ambitious target, employees of Alliance Pharmaceuticals organised various fundraising events, from bake sales and an office tuck shop, to a sponsored bike ride from their offices in Paris to their HQ in Chippenham. With support from a dedicated account manager at Sands and crucially the efforts of their staff, Alliance Pharmaceuticals raised an incredible £30,000 after the company matched the staff's fundraising efforts.

Alliance Pharmaceuticals CEO John Dawson said: "This was an outstanding fundraising effort for a deserving cause and an achievement for which we should all be justifiably proud. I have been absolutely amazed at the energies everyone has put into their fundraising, both personally and in teams, and right across the organisation. Equally amazing was the creativity that was applied to come up with so many different activities, ranging from the physical to the cerebral to the culinary."



Cyclists from Alliance Pharmaceuticals



The sponsored bike ride from Paris to Chippenham



Want to choose Sands as your charity of the year?

Contact us on **020 3897 3444** or **corporate.partnerships@sands.org.uk**

Other ways to support Sands

Running or cycling not your thing? Here are some other ways you can get involved – together we can support anyone affected by the death of a baby, improve the care they receive and save babies' lives.

Collect stamps and foreign coins

Raise funds for Sands by collecting stamps and foreign coins, normally left hiding at the back of a drawer. You could team up with friends, family or colleagues and collect together. Or why not ask your local school, Post Office or Sands Group to join in? Get in touch to find out more.



Give as you Live

Give as you Live is an online shopping scheme and app that turns a portion of every purchase you make through the platform into funds for Sands, at no extra cost to you!



You can sign up for free at giveasyoulive.com/join/sands or visit giveasyoulive.com/install to download the Give As You Live shopping app.

Knit or crochet baby blankets

Sadly, demand for our Always Loved, Never Forgotten memory boxes remains constant and our stock of hand-knitted or crocheted blankets needs to be maintained. These blankets are a very special part of the box, bringing comfort to parents after the death of their baby. The simple pattern can be downloaded from our website or we can send it to you – just get in touch.

Please note that we only use white blankets in our memory boxes.



Give in memory

Raising money in memory of a loved one can be a special way to commemorate their life. It can also provide comfort to those who know that their donations are going to help others going through difficult times. You may wish to ask people attending the funeral or remembrance event of your loved one to make donations to Sands instead of bringing flowers.



Discover more at sands.org.uk/other-ways-to-raise

Make a donation or set up a regular gift to Sands at sands.org.uk/donate

Support for anyone affected by the death of a baby



In order to meet the needs of as many bereaved families as possible, we are continuing to diversify what we offer and how we offer it.

This year has seen the launch of our bereavement support app to enable parents, families and professionals to find the information they need, at the time they need it. We will continue to develop this in response to feedback from users, new information becoming available and as our resources increase.

Our telephone helpline is free to call from landlines and mobiles on **0808 164 3332**, from **9.30am to 5.30pm Monday to Friday** and **6pm to 10pm on Tuesday and Thursday**. You can also email helpline@sands.org.uk and find support in the Sands online community at www.sands.community or via a UK-wide network of support groups with trained befrienders.



We are developing the use of Language Line on the Sands helpline and translating some of our printed materials in conjunction with our international partners to support anyone affected by the death of a baby around the world.

Over the coming year, we will be refreshing and updating our information booklets and memory boxes, to ensure they provide the most up-to-date support for everyone who needs it.

Supporting non-medical professionals

More professionals come into contact with bereaved parents than you might realise. Doctors, nurses and midwives are an integral part of a bereaved parent's experience. However registrars of births, marriages and deaths, funeral directors and other professionals also form part of the circle that parents have to encounter when their baby has died.

Registrars have told us that they don't know what to say to bereaved parents and that they feel uncomfortable and ill-prepared to cope with registering baby births and deaths. They meet bereaved parents at a time when their grief is very raw. Parents may be visibly distressed and in shock, so what may look on the outside like a necessity can be a really traumatic experience.

Sands has recognised the need for specialised training and awareness-raising in these areas and has a dedicated member of staff who delivers talks to non-medical audiences.

These talks are useful to let registrars know that Sands can support them through their experience of supporting parents, and that they can direct parents to Sands.

For similar reasons, we are starting to work closely with the National Association of Funeral Directors (NAFD), whose website now has links to the Sands website and the app. We are planning awareness-raising talks with NAFD members about how to use our memory boxes, and how to help parents and families create memories at funerals.

We are keen to build more partnerships like this to ensure that bereaved parents are able to access support and care from the medical and non-medical professionals they meet following the death of their baby or babies.

To learn more about how we provide bereavement support visit sands.org.uk/support



Nicole Regan-White and family

Sands bereavement support app

We are proud to announce that the Sands Bereavement Support App is here and free to download on your smartphone or tablet. The app carries a wide range of information for anyone affected by the death of a baby, including parents, grandparents, siblings, employers and health professionals.

The app has been in development for a while. Its journey started soon after Nicole Regan-White's baby daughter Jessica died. Nicole worked for Capco, a global management and technology company. Not long after Nicole returned to work, Capco ran a competition that encouraged its employees to nominate a charity that could benefit from the development of an app. Nicole nominated Sands and won the competition.

An app will never replace human contact, and we know how valuable bereaved families have found our helpline and online community. There are times, however, when in the privacy of one's own space, a more discreet option for support might be preferred. At Sands we recognise that one form of support does not fit everyone, and this is another step toward broadening our offering of bereavement support services. We will continue to develop the app, to make it as responsive and helpful as possible.



Stories and poems

At Sands we are often contacted by bereaved parents and families who would like to share a poem about their baby or their personal story with us. Here is a selection of the poems and stories we've received recently.

Whenever I felt lonely

By Emily Neal

Whenever I felt lonely
Fed up or feeling blue
I'd rub my growing tummy
And think of all the things we'd do
Like the first time we would see you
And kiss your button nose
And hold your tiny fingers and
Count your little toes
We'd cover you with kisses
Tend to your every need
And Jake would tell you stories
And teach you how to read
I'd fill your bath with bubbles
Make sure the water was just right
And dry you with a fluffy towel
Then wrap you up so tight
I'd gently rock you in the chair
And hold you to my heart
So you could hear the beat you knew
Right from the very start

These hopes and dreams were borrowed
They were not meant to be
My broken heart is incomplete
Since you're not here with me
I thought it was just perfect
I thought I was your home
But now you are my angel
And I am on my own

So I'll look for you in rainbows
And in the starry sky at night
Take comfort blowing dandelions
Watching the seeds take flight
And every time I walk barefoot
Or paddle in the sea
And feel the sand between my toes
I'll know that you're with me
When the birds are singing
And the morning sky is blue
I'll look for clouds and sun beams
And I'll always think of you

For Robin, I'm your mummy
And I've known right from the start
I loved you more than words can say
With each beat of my heart
And since your heart stopped beating
Mine's been filled with pain
But it will beat for both of us
Until we meet again.



Paint a smile in your grief

by Jackie Ellerby

Paint a smile in your grief
And wear it every day
Pretend like there is nothing wrong
And tell them you're okay

Paint a smile in your grief
And you will find in time
People will ask "How are you?"
And you'll learn to say "I'm fine"

Paint a smile in your grief
Walk with your head held high
Those passing faces on the street
Will not see through your lie

Paint a smile in your grief
Don't let them see you cry
They'll never know how it feels
To have to say goodbye

Paint a smile in your grief
You somehow must go on
On days when you are feeling low
Believe you can be strong

Paint a smile in your grief
Your life will forever alter
The person you were has
changed for good
And some days your voice will falter

Paint a smile in your grief
The hardest part isn't
saying goodbye
It's having to learn to live without
And with all you have, you'll try

Paint a smile in your grief
Keep strong and always calm
For they will never understand
The void that's in your arms

Paint a smile in your grief
All you have is memories
And sometimes it will hit you hard
And beat you to your knees

Paint a smile in your grief
Each moment you're apart
No one can fill the gap that's there
Or the hole that's in your heart

Paint a smile in your grief
You've met with your worst fears
You came out on the other side
Though different, filled with tears

Paint a smile in your grief
For there is not one other
The strongest person you'll
ever meet
Is a smiling, grieving mother.

I forgot

by Dee Longhurst

I forgot to think of you today.
And yesterday.
And perhaps the day before.
When someone asked me
How many girls I have
I told them three.
And I usually mean it's four.
I haven't visited your grave for a while
Or wished that you were here.
Your headstone is looking slightly green
And your flowers were eaten by deer.

I saw some yellow roses today
But I didn't think of your death
I didn't remember the sympathy cards
Or the messages that were left.
I didn't kiss your photo
Or caress your lock of hair.
I didn't dream of holding you
Or long to have you there.

I guess they call this 'moving on'
But I feel I am being unkind
My future awaits, our lives go on
And I don't want to leave you behind.
I miss you now that I've remembered
(I hadn't forgotten you altogether)
I may not think of you every day
But I love you now and forever.

Share your poems and stories at
sands.org.uk/shareyourstory

Our precious son, Altair

by Shema Tariq

My waters broke on the tube on 8 June 2017.

I was rushed into hospital and two days later our son, Altair, was stillborn at 21 weeks. Tiny but perfect in every way. This was my first pregnancy after years of infertility, conceived on our fourth cycle of IVF.

Despite having worked as a doctor for nearly 20 years, many of those years working in research on women's health, it never occurred to me that I might not get to take my baby home.

The grief of losing your child is unimaginable. You're not only grieving the present, but a future that's left unmade. A lifetime of milestones that will never be reached.

On 10 June 2018, we celebrated the first anniversary of Altair's birth. We have managed to reach a place where my husband Ian and I feel at peace. Joy has come back into our lives. We have found a way to continue IVF and hold on to hope.

We miss our baby boy, Dylan

by Kate Sharp

My partner Andy and I had our first child together, Finley, on 18 August 2015. Thirteen months later I was pregnant again.

During our 20-week scan, we found out that one of our twins had a heart condition called Transposition of the Great Arteries. He was due to go for open heart surgery as soon as he was born.

Unfortunately, our twins were born at 30 weeks by emergency c-section. Dylan was too small for the operation and he passed away 16 hours after birth.

The nurse who looked after Dylan was so kind, she stroked his head, talked to him, bathed him, took photos, and did hand and footprints.



In the meantime, it's important for me to share our story and to end the silence around baby loss. It happens. It's tough. We need to find ways of talking about it.

If our story can make one other person feel less alone, then it means that our son's death was not meaningless.

In memory of Altair Taylor, 10 June 2017.

Our bereavement midwife gave us a memory box containing all of his tubes, the blanket he was lying on in his incubator – still with his smell on – a lock of his hair and his first tiny nappy.

The Liverpool Women's Hospital have a chapel and Reverend Anne came over to the Wirral to lead Dylan's funeral. The work that goes on in this hospital is extraordinary.

It has been so hard to cope with the grief and happiness of a newborn, especially for Andy's eldest son Ethan, nine, who has lost his baby brother. However, by talking about Dylan, it helps us to remember he is always a part of our family.

Our triplet heartache

by Catherine and Mike Blewitt

At our-eight week scan, myself and my husband found out we were having naturally conceived triplets, we couldn't believe it and were over the moon. We felt like the luckiest parents alive and I absolutely loved my growing bump. We set up an Instagram page to blog our story as we wanted to remember each step of our journey.

Fast forward to our 20-week scan, everything was perfect. Our babies were developing and growing exactly as they should be. Two days later, on 19 May, I went into pre-term labour, without knowing I was actually in pre-term labour. We rang our hospital and explained the pains I was having and they asked me to go in to be on the safe side. The journey to the hospital was awful, it seemed to take forever and my sense of panic was increasing. I asked my husband to drop me off outside as I was in so much pain and knew I wouldn't be able to walk from the car park.

As I arrived I was feeling more and more pressure and was becoming increasingly scared as to what was happening. As soon as the doctor managed to get me into a room the first of three sets of waters broke. My husband still wasn't with me as he was parking the car, I will never forget the look of fear on his face when he walked into the room to see me lying on the bed in labour.

I don't know where it came from, but I got this overwhelming strength which enabled me to be in control during labour and deliver all three babies and all three placentas myself. Jack, Lottie and Rosie were given to me to hold as soon as they were born, their soft warm skin is a feeling I will hold onto for the rest of my life. I remember looking at them, they were perfect, nothing was wrong with them. Sadly, after about an hour and a half they peacefully passed away in my arms. In one night we had lost our whole family, our precious babies and everything we had ever wanted had been taken away from us!

At Heartlands Hospital, where our babies were born, we were provided amazing support by the Eden bereavement suite who has specially-trained midwives to support families like ourselves. One particular midwife, Nicky, was amazing and she made amazing memory boxes including, photographs, teddies, hand and footprints... our beautiful babies were allowed to stay by our side in hospital due to the cuddle cots which help preserve the babies.

We stayed there for three nights and could make amazing memories with our babies, we could take them to their special garden outside, read them stories, tell them about their mummy and daddy and enjoy time together. While we were in the hospital, myself and my husband decided we wanted to raise money to provide the hospital with another cuddle cot as they only had two at this hospital.

We decided to plough our energy into fundraising to help and support families like us in the future. In what has been the worst time of our life, this fundraising has given us the strength we need.

Myself and my husband promised each other that we would be open and talk about our feelings. We are so lucky to have amazing family and friends who are open to talk to us about our beautiful babies. The Sands #FindingTheWords campaign is helping raise awareness that every baby should be talked about and it's good to be open and share how you are feeling.

Discover more stories at
sands.org.uk/40stories

We'd love to hear your thoughts on
our magazine via our online survey
surveymonkey.co.uk/r/spotlightonsands

Sands Bereavement Support App

for anyone affected by the death of a baby



Support for families



Making difficult decisions



Share your story



For professionals

- Support and information for bereaved parents and families
- Information for healthcare professionals who would like to know how best to support bereaved parents

Download now



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