

Impact Report

2017-18

Supporting bereaved parents,
saving babies' lives



VOICES OF IMPACT

Parents and families who have experienced the death of a baby are at the heart of everything we do

Sands helped when we had no clue what to do. We had received the devastating news that our baby had died and had no idea what happened next. Sands helped us through those horrific hours and days. We are forever grateful.

Jo

My support, my strength, my advisors and my survival. Twenty-six years ago you stood beside me, held my hand and helped me breathe again. Thank you.

Rae

Sands is the family you never want to be part of, but the family you now can't be without. Xx

Sinead

Sands to me means hope, a lifeline for parents, like me, who have suffered the loss of a baby. To be able to communicate with people who understand what it's like to lose a child and be there for us. Always.

Amanda

Sands saved me ♥

Melanie

OUR SHARED VISION

Over the past 40 years, Sands has grown into a national charity with a powerful vision shared by dedicated volunteers, fundraisers, members, donors, healthcare professionals, partners, staff and bereaved parents and families. These are the voices of our impact.

our vision at Sands is for a world where fewer babies die and anyone affected by the death of a baby receives the best care and support for as long as they need, wherever they live in the UK.

Everything you'll see in this report – from the support we provide and the workshops we run to the research we fund and the ways we raise money – is focused around our three core aims:



To support anyone affected by the death of a baby.



To work in partnership with health care professionals to ensure that bereaved parents and families receive the best possible care.



To promote improvements in practice and fund research to help reduce the number of babies dying.

VOICES OF IMPACT

“ The beach is vast, empty
I am lost and alone
Trapped by the loss of my little girl
Grief is overwhelming
But there is a grain
Among the millions
A friendly face, kind words
From people who understand
my pain.

Chris

“ When you don't know
who else to turn to,
who will listen, who
will understand and
who will ultimately get
you through the single
worst thing to happen
to you; this is Sands.
And I thank you.

Natalie

“ Sands charity is each of us
supporting each other. Baby
loss is so life-changing and
only people that have been
there can really understand.
Sands is the glue that brings
us all together, supporting
each other and really
understanding.

Chris

“ Sands is amazing. No-one can
underestimate the safety-net
of unconditional support they
provide; even just knowing
they are there, for that one
moment when the darkness
wholly consumes, when my
breath is stripped away and
reality shatters my heart again.

Carolyn

WELCOME



It is crucial to reflect on the impact of our work, on whether we are achieving our ambition to reduce the number of babies dying, and to provide the best possible care and support for anyone affected by the death of a baby. This impact report allows us to look back over the last 12 months and see how much has been achieved towards these goals.

This year is particularly significant as we are commemorating our 40th anniversary. We have come a long way since two bereaved mothers, Bel Mooney and Hazelmanne Lewis, founded Sands in 1978.

Thanks to all of those who have been involved over the years, Sands has grown and flourished and we are now providing more support than ever before.

We are always looking to the future and want to continue to be the voice of bereaved parents, ensuring that we are making a real difference.

I hope we can continue our journey together and ensure everyone affected by the death of a baby receives the help and support they need, whenever they need it.

Dr Clea Harmer
Chief Executive, Sands



It has been an enormous honour to be the Chair of Trustees for Sands, and I am proud of how much has been achieved over the last few years to reach even more parents with our support, to raise awareness of the issues surrounding stillbirth and neonatal death, and to reduce the taboo associated with these deaths.

We have also made significant contributions to improving bereavement care and to the continued focus on reducing the number of babies dying.

All of this has been possible thanks to the commitment and enthusiasm of everyone at Sands, and as I hand over to the new Chair, Oliver Reichardt, I know that the future will bring continued opportunities for Sands to touch the lives of all those affected by the death of a baby.

With many thanks for all your support.

Angela McCafferty
Chair of Trustees, Sands

With many
thanks for all
your support

WHERE WE CAME FROM...



In 1975, I gave birth to a baby boy who was stillborn. At the time, partners were not encouraged to be with you during labour. Maternity units acted on an 'out of sight, out of mind' basis, with the stillborn baby being whisked away before the mother could see him.

Partners were told to register the birth and grant permission to the hospital to bury the baby. They were advised not to talk to the mother about the baby as that would upset her. Never mind the fact that fathers also had feelings.

It's difficult to mourn your baby with no tangible memories. People cross the road to avoid talking to you. The thought of the next baby was offered as a sticking plaster to cure the pain of the loss.

I reached out through the press to try and gain support for educating professionals on the needs of bereaved parents. The response from bereaved parents was overwhelming and indicated a clear need for support. From that I went on to found Sands.

I am stunned by how Sands has grown into the effective, influential organisation it is today. I had hopes 40 years ago that it would be a viable organisation, but never dreamt it would be as powerful as it is.

Hazelanne Lewis
Co-Founder, Sands



It must be so hard for people to imagine a time when there was no help for the mothers or fathers of stillborn babies, and no understanding of the effect grief can have for years. After all, how can such issues be addressed if they are never acknowledged?

That is how it was at the end of 1975, when my second son was stillborn. Looking back I can remember a terrible silence.

As a journalist I was able to pour my grief into words – and tell the readers of *The Guardian* how it felt to bear a stillborn child. The rest is history.

There is still much work to be done in addressing totally unacceptable standards – those shocking statistics which mask the incalculable sorrow of so many families.

I give thanks for Sands and for their hard work which ensures that no grieving parent nowadays need ever reach out and find no help there.

Bel Mooney
Co-Founder, Sands

Sands means so much to me personally, but what really matters is that this charity represents an important fight. Those who lost their precious babies for avoidable reasons deserve answers – and justice. Sands is their voice.

OUR JOURNEY

40 years of being a lifeline and a voice of bereaved parents and families

“45 years ago, no-one spoke, you were told to put it behind you. 40 years ago, Sands was started and I was allowed to talk, to grieve. Today, I will never forget, but I have a more settled, content reflection. Thank you, Sands.”
Christina, Founder member, Sands

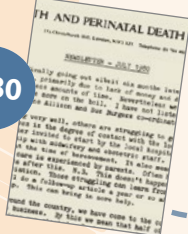
This year marks 40 years since Sands was founded. To recognise this, we're honouring the achievements of everyone who has worked with us, including volunteers, befrienders, fundraisers, healthcare and other professionals, to support bereaved families, improve bereavement care and reduce the baby death rate in the UK.

1978
Sands founded

By bereaved parents for bereaved parents: 40 years ago, two bereaved mothers, Bel Mooney and Hazelanne Lewis, found there was no support available for them following the deaths of their babies. Realising there were many bereaved parents across the UK left similarly devastated and without support, they founded Sands in 1978. At that time in the UK, most parents were not allowed to see, hold or have a funeral for their babies. No photographs were taken, and they could not put their baby's name on the stillbirth certificate.

First newsletter sent out

1980



1981

Registered as a charity

After three years of meetings, letters and consultations with the Charity Commission, Hazelanne and Bel managed to register the Stillbirth and Perinatal Death Association (SPDA) as a charity.

1984

Name changed to Sands, (the Stillbirth and Neonatal Death Society).



Esther Rantzen's documentary *The Lost Babies* shown on TV

It was the next leap forward as tremendous public interest reflected in the formation of many new local support groups across the UK.

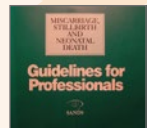
1987



New teardrop logo introduced

Sands logo was then refreshed in 2006, followed by a new look for publications and merchandise.

1991



First Guidelines for Professionals published

New editions were released in 1995, 2007 and 2016.
[More on page 23](#)

1986

First support booklet published called *Saying goodbye to your baby*. New editions were released in 2003, 2010, 2011 and 2016.
[More on page 28](#)



1985

Helpline set up



"I've never been really good at remembering dates. It's people I remember. Or more accurately voices. I've heard a lot of voices on the Sands helpline. And always, the fragile voices of grief."

Patrick Wilcockson, *Helpline Co-ordinator and Lead*

[More on page 26](#)

1992



Coronation Street portrays baby death

Katie McDonald, the only daughter of Coronation Street's character Liz McDonald, was born prematurely and died at one day old.

Sands Act lowers stillbirth definition

Definition of stillbirth was reduced from 28 to 24 weeks after the bill received royal assent.

[More on page 11](#)



First discussion day for fathers

The workshop focused on acknowledging and addressing the needs of fathers and was followed by considerable press coverage, including *And father cries as much as any* in *The Guardian*. The second workshop took place in 1992.



1993



Teardrop sticker scheme introduced

By attaching a discreet label to a bereaved parents' medical notes, the new scheme aimed to support and inform healthcare professionals.

First Sands conference on reducing the incidence of stillbirth.



1994

Stillbirth and neonatal death rate is **20 babies a day**



First Sands Awareness Week

The week raised funds for the helpline, which was handling 4,000 calls a year. Actor Bill Cryer helped to launch the week.

[More on page 33](#)

2003



First Sands website launched

[More on page 37](#)

2002



First Baby Loss Awareness Week

Launched as a day and extended to a week with an aim to unite people across the UK who had been touched by the loss of a baby during pregnancy, just after birth or in infancy.

[More on page 40](#)

2000



First Garden Day and Remembrance Event

[More on page 30](#)

2004

First Lights of Love service

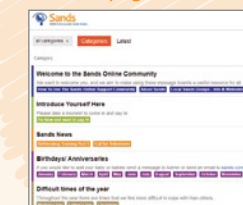
[More on page 30](#)



2005

Online community launched

[More on page 28](#)



Sands joins the International Stillbirth Alliance (ISA) board and attends a conference in Japan

ISA is a collaborative global effort to reverse stillbirth rates and improve bereavement care. Our association with ISA is formative in breaking the taboo and revising policy.



2009



Memory boxes launched

Always free to bereaved parents, these were made free to hospitals in 2017.

More on page 29



Why 17? Campaign

As part of Sands Awareness Month, this campaign raised awareness of 17 babies being stillborn or dying shortly after birth in the UK.

Saving Babies' Lives Report published

Our first national report highlighted that some babies' deaths are potentially avoidable and called for collaborative commitment to address these.



2010

BEREAVEMENT CARE NETWORK

Online Network for Bereavement Midwives launched

In collaboration with Bliss and the Royal College of Midwives (RCM), the UK's first online network was launched for bereavement midwives and other health professionals.



Bereavement Care Report published

The report investigated standards of bereavement care in maternity units across the UK. In 2016, Sands published results of a second audit of bereavement care provision.

First research funded by Sands

A big step that signified Sands' determination to prevent baby deaths as well as support those affected by stillbirth and neonatal death.

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2011

Sands Audit Tool for maternity services introduced

The audit tool was developed to help those responsible for commissioning and providing maternity services to assess the quality of care they provide to bereaved parents and identify improvements.



Why 17? Photo Exhibition at OXO Gallery hosted

The exhibition showcased 17 photos of pregnant women who have been affected by the death of a baby.



2012



Preventing Babies' Deaths report launched

The second Sands report called for better data and research into baby deaths, increased public awareness of stillbirth risks, better reviews and improved bereavement care.

New training for Groups

Training for new and existing local groups offered support and resources to provide services for the bereaved parents in their communities.

2013



MBRRACE-UK starts collecting data on baby deaths

Mothers and Babies, Reducing Risk through Audit and Confidential Enquiries (MBRRACE-UK), with Sands as a member, begins a new national data collection programme.

Reception at No10

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



2016

All-Party Parliamentary Group (APPG) on Baby Loss formed

APPG brought MPs and peers together to improve care for bereaved parents and to raise awareness of the issues around baby death within Parliament.



2017



Sands advises on storyline for Coronation Street

With Sands input, ITV's Coronation Street tackled the difficult subject of late miscarriage when Michelle Connor's baby died at 23 weeks.



Sands advised on storyline for EastEnders

Sands worked closely with scriptwriters and actress Rakhee Thakrar whose character had a stillborn baby. Praised for its realistic and sensitive portrayal of baby loss, the BBC show raised national awareness. Rakhee became a Sands ambassador.

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2015

2018



Sands launched saferpregnancy.org.uk

More on page 18



National Bereavement Care Pathway launched

More on page 20



#15babiesaday initiative

Highlighted that 15 babies die shortly before, during or shortly after birth in the UK every single day.

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Perinatal Mortality Review Tool launched

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THE GLOBAL PICTURE

Stillbirths and neonatal mortality: a worldwide challenge



Every year, an estimated 2.6 million babies are stillborn across the world. Another 2.6 million die in the first 28 days of life – the neonatal period*.

*WHO and UNICEF, 2017

One of the UN's Sustainable Development Goals (SDGs) is to end preventable deaths of newborns and children under five years of age by 2030, with all countries aiming to reduce neonatal mortality to at least as low as 12 per 1,000 live births.

Although the UK met the global target some 40 years ago, the rate of improvement has slowed compared with other EU countries.

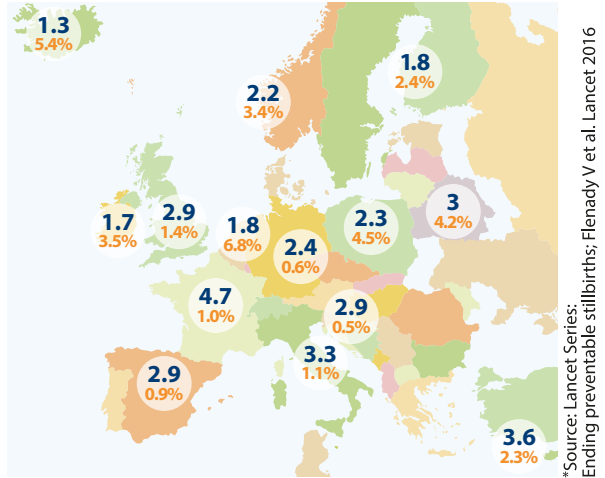
Stillbirths

Across the world, the rate of stillbirth varies by region and is correlated with access to maternal healthcare. This indicates that the majority of stillbirths are preventable.

The UK ranks 19th out of 38 high-income countries in Europe for stillbirths after 28 weeks with a stillbirth rate of 2.9 per 1,000 live births*. Between 2000 and 2015, the annual rate of reduction in the UK was only 1.4%. During the same period, the Netherlands achieved a 6.4% decline every year.

Neonatal mortality

Again, the UK ranks 19th out of 38, with a rate of 2.7 deaths per 1,000 live births*. This is in contrast to countries such as Slovenia, which ranks third and has a neonatal mortality rate of just 1.4 per 1,000 live births.



■ Stillbirth rate per 1,000 live births
■ Annual rate of reduction of stillbirth (2000 – 2015)

*Source: Lancet Series: Ending preventable stillbirths; Flennady V et al. Lancet 2016



THE NATIONAL PICTURE

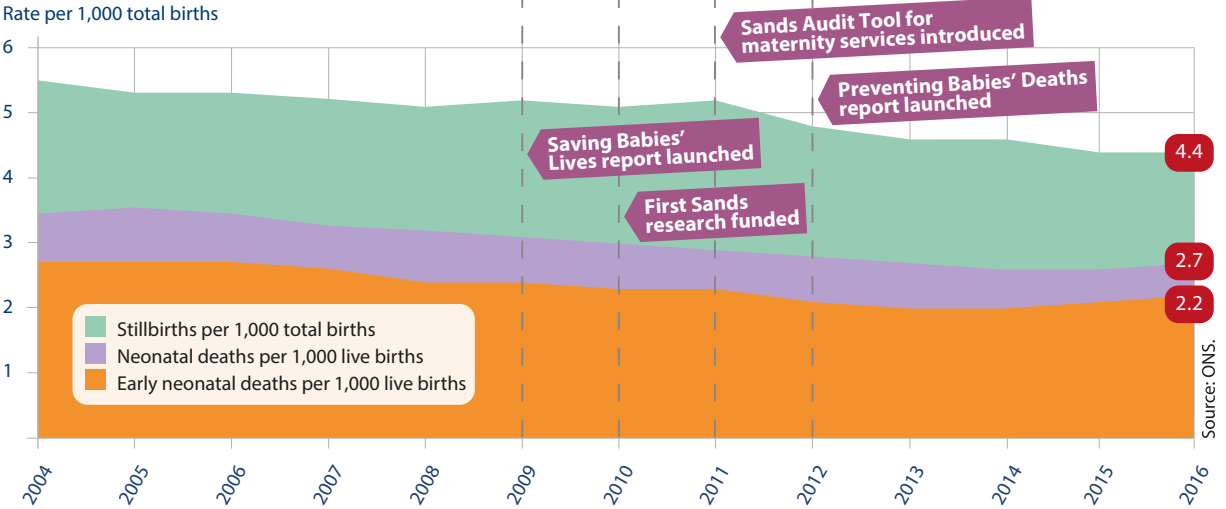
UK stillbirth rate at an all-time low

In recent years, we've witnessed a significant reduction in the rates of stillbirths and neonatal deaths. Whilst this is an amazing achievement, every day 15 babies die in the UK either before, during or shortly after birth. We think many more of these deaths are potentially avoidable.



Through research and review of babies' deaths, we can improve bereavement care and save future lives. Unless more is done, over 10,000 parents will be affected by the death of a baby every year and the need for the bereavement support that Sands offers will remain.

The fall in the rate of babies who die



DID YOU KNOW?

£72 million the economic annual cost of stillbirth to the UK

*Stillbirths: economic and psychological consequences. Heazell et al, Lancet 2016

SANDS BILL BECOMES LAW

Following lobbying by Sands and its groups, the Stillbirth (Definition) Act came into force on 1st October 1992, changing the definition of stillbirth to include babies born after 24 weeks' gestation, which was previously at 28 weeks.

THE DIFFERENCE WE MADE

Our impact in numbers



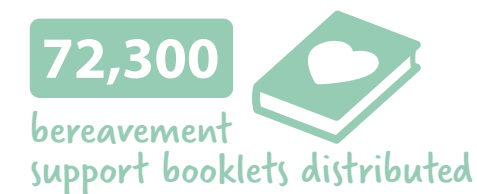
We helped at least 517 bereaved parents and families per month, thanks to our UK-wide volunteer network.



We provided a safe online space for 1,059 bereaved parents and families to connect and support each other 24/7 through our moderated online community.



We responded to 2,679 helpline calls and 1,810 emails from bereaved parents and families to help guide them through the most devastating moments in their life.



Our online bereavement support resources have been accessed 44,000 times by bereaved parents and families.



We provided 2,084 memory boxes for families to create precious memories of their baby.



We provided 5,215 family support packs to parents who have been affected by the death of a baby.



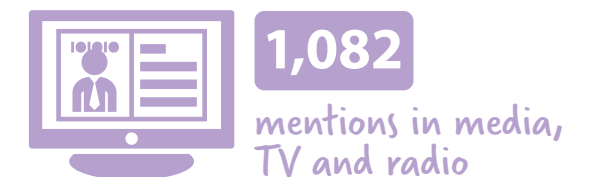
National Bereavement Care Pathway has been piloted across 11 sites in England since launch in 2017.



2,640 healthcare professionals improved their bereavement care skills with our training.



We directly funded 4 new research studies that will impact on the numbers of babies who die and make a difference to the experience of parents and families when the worst does happen. £1,000,000 has been invested in research since 2010.



We were mentioned 1,082 times in online and print media, TV and radio, raising awareness of stillbirth and neonatal death.

...AND WHERE WE'RE GOING

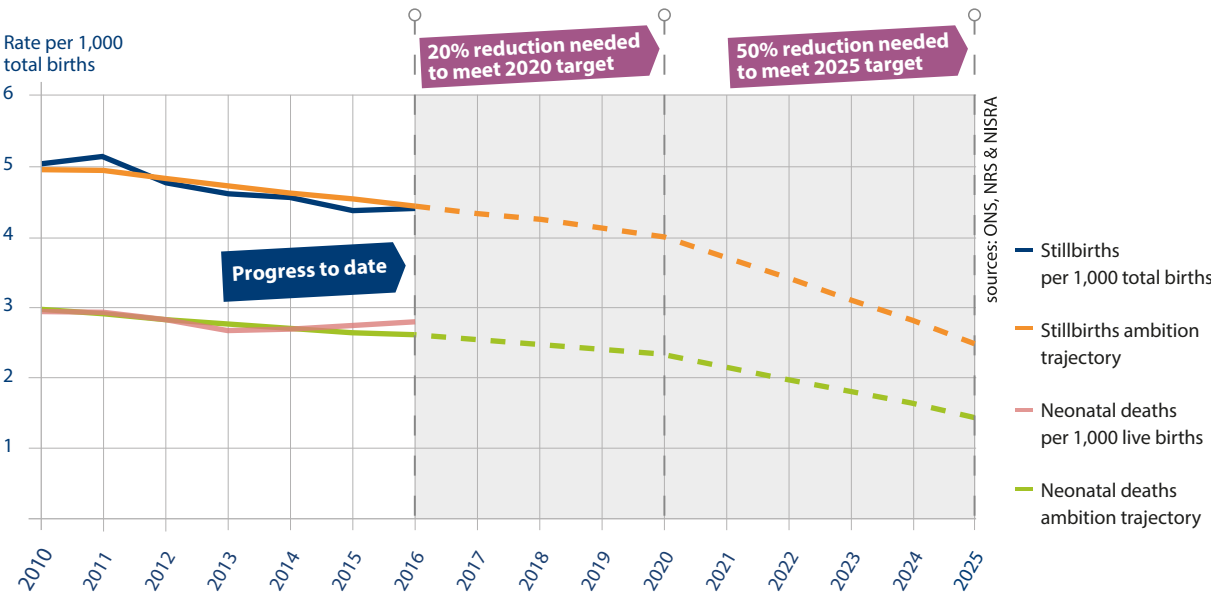
Our vision is for a world where fewer babies die

The Department of Health committed to halving the rate of stillbirths and infant deaths in England by 2025.

To reach this goal, governments in the UK will have to at least double the rate at which they are reducing baby deaths every year between now and then.

It is one of Sands' six strategic commitments to push for the 2020 ambition to be met.

UK stillbirth and neonatal mortality rates (2010-2016) and National Maternity Safety Ambition trajectories



Government targets*



England:
reduce by 20% by 2020
reduce by 50% by 2025



Scotland:
reduce by 15% by 2015
reduce by 35% by 2020

*Northern Ireland and Wales have no set targets

OUR STRATEGY 2017-2020

Four objectives to realise our vision

1

To reduce the number of babies dying before, during and shortly after birth

2

To ensure the right care and support is available at the right time after the death of a baby

3

To grow as one strong, sustainable and effective organisation

4

To raise awareness of the issues relating to stillbirth and neonatal death

WE ARE COMMITTED



To reduce the number of babies dying by at least 20% by 2020



To have a bereavement lead in every Trust or Health Board and at least one bereavement suite in every hospital



To implement a National Bereavement Care Pathway to make sure that every parent receives equally excellent bereavement care



To ensure a high-quality review of care is carried out, in partnership with parents, after every baby's death



To raise awareness of the issues surrounding stillbirth and neonatal death and to reduce the taboo associated with these deaths



To ensure every bereaved parent receives a free memory box

A YEAR INTO OUR STRATEGY

In 2017, we launched our three-year strategy to unite the baby loss community in pursuit of our shared vision: a world where fewer babies die and anyone affected by the death of a baby receives the support and care they need. The strategy is broken down into four objectives that guide our work.

STRATEGIC OBJECTIVE
1

To reduce the number of babies dying before, during and shortly after birth

Influencing change through research, policy and communications

By funding world class research and promoting better quality reviews of care, we are increasing understanding of why babies die in order to identify and implement actions to save babies' lives.

Our close collaboration with Royal Colleges, key influencers and other charities in the sector helps us build authority and the evidence base for our policy messages.

We are also working with policy makers and politicians to change national policy in England, Scotland, Wales and Northern Ireland and obtain widespread commitment, from national to individual level.

DID YOU KNOW?

Sands research and prevention team was set up in 2008 and undertook the first bereaved parent survey of experiences of care.

Our research investment

Sands research fund has awarded close to £1 million of grants since 2010, supporting research that will impact on the numbers of babies who die and making a difference to the experience of parents when the worst does happen.

our research investment has more than doubled*

*as a proportion of total expenditure

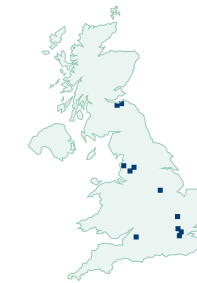
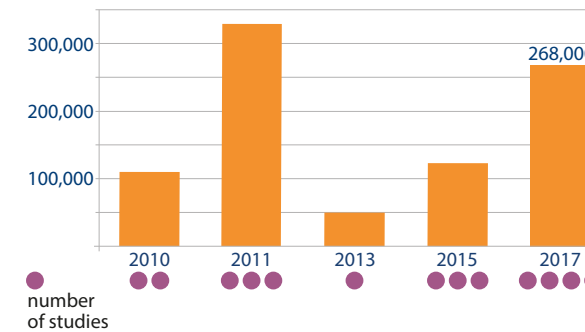


We prioritise studies that examine the underlying causes of stillbirths and neonatal deaths, find better ways to identify and manage at-risk pregnancies, as well as those that will lead to better bereavement care. Studies have looked at how to use scans to predict risk of a baby's death at the end of pregnancy, how fetal movement monitoring might reduce stillbirths, post-mortem, challenging thinking about what investigations give the best information as well as hearing from parents about their experiences of consenting to autopsy and how religion and culture play a part. Another study has calculated the economic cost of stillbirth. All this adds to the body of knowledge that is vital to understanding why babies die and to change the experience of families now and in the future.

£1,000,000 invested in research since 2010



Sands research fund



Sands-funded research teams

SANDS-FUNDED RESEARCH

In 2010, we funded our first research projects, a step that signified Sands' determination to prevent baby deaths.

FIRST NATIONAL REPORT

In 2009, our first national report *Saving Babies Lives* highlighted that many babies' deaths are potentially avoidable, challenging long-held views that nothing could be done. We called for six key actions, all of which are now central to maternity safety policy.



270 parents were surveyed



80% of families said the death of their baby had an impact on the wider family



33% said their relationships had suffered as a result



25% of parents said their incomes were affected by having to change job or career

Case study of a research project

The Midlands and North of England Stillbirth Study, which we co-funded, looked at links between the characteristics of mums-to-be and stillbirth. It found that pregnant women in the last third of pregnancy are less likely to have a stillborn baby if they go to sleep on

their side. The study estimates that if all pregnant women in the UK followed the side-sleeping guidance around 130 baby deaths might be prevented every year. We're using this information to empower women to keep their babies safer during pregnancy. The new advice is on our Safer Pregnancy website.

Safer Pregnancy



Launched in 2017, the Safer Pregnancy website offers straight-talking advice for mums-to-be who want to know what they can do to keep themselves and their baby safer.

saferpregnancy.org.uk



59,458 website visitors
accessed information
103,917 times



10.3% are
returning visitors



23.5% of visits
to "Keeping Healthy"
page

A grant from Google Ads enabled us to engage with more people online. This means we can share the vital messages about staying healthy and reducing possible risks with a wider audience.

Perinatal Mortality Review Tool is finally here



The quality of maternity and neonatal care reviews varies significantly across the UK. Championed by Sands since 2012, in partnership with the Department of Health, the PMRT is now available to use free of charge in England, Scotland and Wales. The Tool is vital in supporting hospitals to conduct high-quality reviews after a baby has died to learn lessons and improve future care.

Even for deaths at the very end of pregnancy, reviews are not always carried out:

"1 in 4 reviews couldn't be assessed as they lacked information",

according to the Each Baby Counts initiative run by the Royal College of Obstetricians and Gynaecologists (RCOG).

A key principle of the PMRT is to include parents' perspectives of their care when reviewing their baby's death. It is our aim to help parents understand why their baby died.

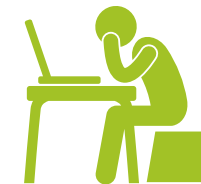
146 Trusts and Health Boards are now registered to use a new tool to review baby deaths

Parents' voices at the heart of what we do

We aim to ensure that parents' voices are at the centre of policy to prevent baby deaths, whether it's improving how we learn from deaths or shaping research that may impact on improvements to maternity services.

We contributed to NHS England's new Learning from Deaths guidance for engaging bereaved families in investigations, ensuring it reflects parents' views and needs.

We asked parents what they thought about the Secretary of State's proposal to extend coroners' jurisdiction to stillbirths. The findings of our survey with parents were shared with MPs leading the call for a change in the law.



477 parents
responded to
online survey

91% thought that
coroners' involvement
was a good idea



The Saving Babies' Lives Care Bundle really does save lives

Over the last five years, Sands has been involved in developing the Saving Babies' Lives Stillbirth Care Bundle.

The NHS England care bundle is a set of four interventions aimed at helping healthcare professionals improve care in pregnancy and labour to prevent stillbirths.



100+ units in
England are now using
at least one element
of the bundle



20% reduction in stillbirths
between 2013 and 2017 in 19
units that took part in the
evaluation

While the reduction can't exclusively be linked to the bundle, it is certainly a significant improvement in care that's having an impact on stillbirth rates in England.

To ensure the right care and support is available at the right time after the death of a baby

National Bereavement Care Pathway



The standard of care in the UK varies between regions. We're working to ensure that excellent, evidence-based care is offered to all bereaved parents wherever they live. This is why we have developed a National Bereavement Care Pathway (NBCP) in collaboration with Royal Colleges and other key influencers. The Westminster Government has supported the roll-out of the NBCP in England.



11 pilot sites in England since launch

According to an evaluation of eleven pilot sites:



75% agreed bereavement care had improved in their Trust

The NBCP Core Group



The NBCP standards include:

- All bereaved parents given opportunities to spend time making memories with their precious babies;
- A dedicated bereavement room available and accessible in every hospital;
- Bereavement care training for all staff who have contact with grieving parents;
- Support for healthcare staff dealing with the trauma of baby loss so that they are able to care for bereaved parents.

“It's shocking that there is a post-code lottery of care. Every hospital should have a bereavement midwife. Just to have someone to know how to deal with death and what to expect – simple things like that made such a difference. It helps so much to have support at a time like that. If there is a consistent level of care, it helps you through the grieving process.”

Viki

Bereavement care training

The care that parents receive when their baby dies is of crucial importance for their physical and mental health. Whilst no level of care can remove the grief, good care can make a devastating experience feel more manageable. Bereavement care varies across the country and training is a key to ensuring that a minimum standard of care is offered.

“An excellent day, as it prepares you for working with bereaved parents – from discovery of loss or death, to the next pregnancy if planned.”

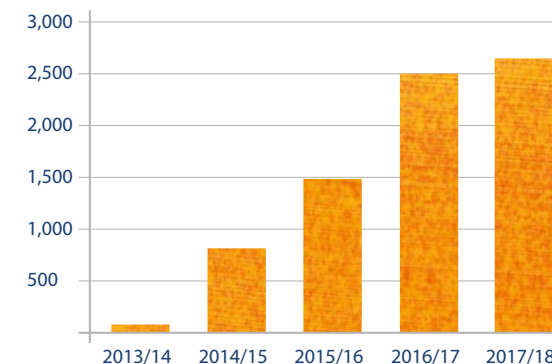
Since launch of our bereavement care training in 2014:

We've trained **7,524** healthcare professionals

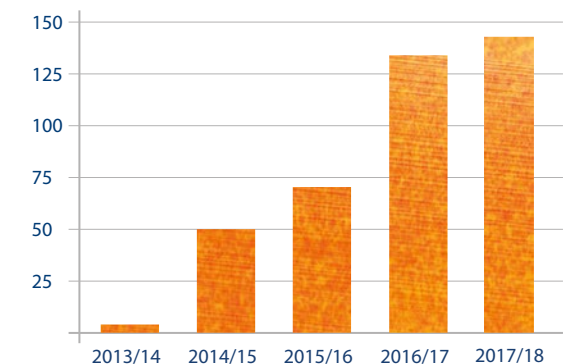
402 training days hosted

“Providing care for women who may experience a still-birth has been one of my biggest fears. This course has provided me with the confidence. Most useful study day we've had!”

Professionals trained



Training workshops



Growing the training to accelerate progress

In 2014, we only offered training to midwives. We have expanded our range of courses and now train:

- Multidisciplinary groups (attendees have included sonographers and obstetricians)
- Midwives • Student Midwives • Doulas
- Interpreters • Counsellors • Health Visitors
- GPs (via online learning)

Our training workshops receive consistently positive feedback, with the majority of participants stating that they feel more confident in communicating sensitively with bereaved parents.



“I've gained information and skills, which I can apply to my practice to deliver bereavement care confidently. Very useful for development as a midwife; should be compulsory on all midwifery courses.”



“Brilliant study day – the most useful I have ever been to. Great open, supportive and non-judgemental atmosphere. Every student midwife needs to do it. Thanks a million!”

Bereavement care

We work towards ensuring that the right care, support and environment is offered by all healthcare professionals, Trusts and Health Boards, which means that every parent whose baby has died has access to a bereavement suite, wherever they live in the UK and every hospital has a bereavement midwife.

Pregnancy loss and the death of a baby: Guidelines for Professionals 4th Edition

Our flagship publication for health and social care professionals, *Pregnancy loss and the death of a baby: Guidelines for Professionals*, achieved a fundamental change in the way bereaved parents and their babies are cared for today.

The Guidelines cover losses at any stage during pregnancy, including early and late miscarriage and termination for fetal anomaly, as well as stillbirth and care for very ill babies and those who are likely to die shortly after birth. As well as describing what constitutes good care, the Guidelines offer practical guidance on how to meet parents' needs.



FIRST GUIDELINES FOR PROFESSIONALS

In February 1991, we published the first *Guidelines for Professionals*, which signalled Sands' ambition to not only support parents, but also to improve the care they received. The publication was described as “excellent” and “powerful” by Virginia Bottomley, Minister for Health at the time. She ordered 2,500 copies to distribute to district health authorities across the UK. The 2nd edition was published in 1995 followed by the 3rd edition in 2007 and the latest 4th edition in 2016.



BEREAVEMENT SUPPORT

We offer a range of bereavement support services, including local bereavement support groups, the free telephone helpline, online community, printed and online materials.

Befrienders

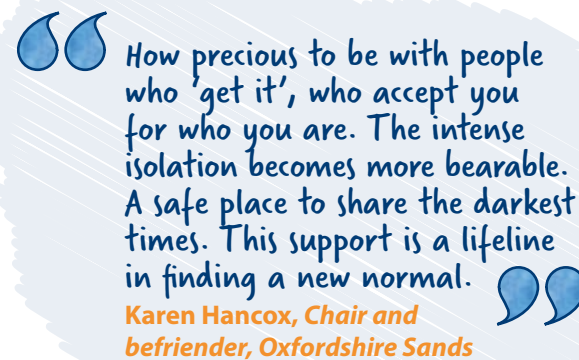
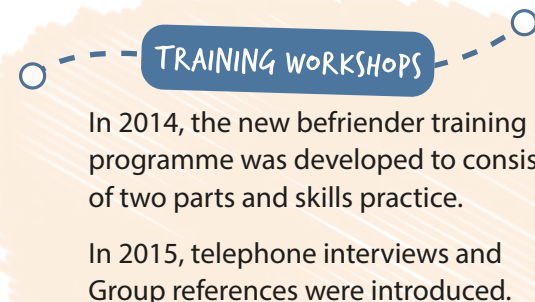
Our volunteer befrienders play a vital role in offering support to bereaved families throughout the UK. The reassurance of speaking to someone else who has had a similar experience is invaluable.



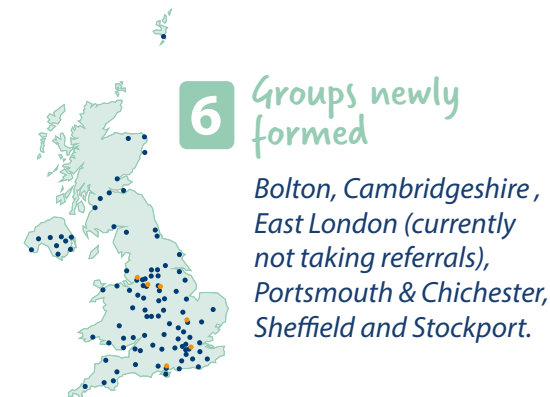
DID YOU KNOW?

The first befriender training workshops took place in 1984.

We're updating the second part of our befriender training programme to ensure it is evidence-based and offers an excellent foundation to support anyone affected by the death of a baby. We've introduced a probationary period for all new befrienders, who need to be at least two years beyond their own bereavement.



Local volunteer groups



Helpline

Our helpline offers support to anyone affected by the death of a baby. To this day it continues to be an important part of our support services for parents and families struggling to cope with baby loss.

0808 164 3332
helpline@sands.org.uk



1,363 hours of support provided to bereaved parents, family members and health-care professionals who called our helpline

we responded to...
2,679 helpline calls
1,801 emails

DID YOU KNOW?

Sands helpline was set up in 1985.



4,489 conversations held by our helpline team to help guide the callers through most devastating moments in their life

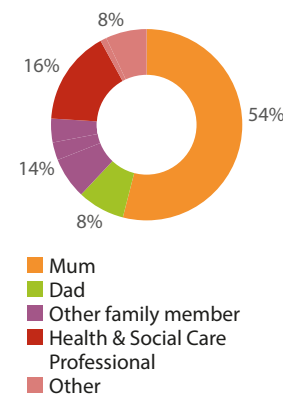


43% of calls and emails are made within the first two months of a bereavement

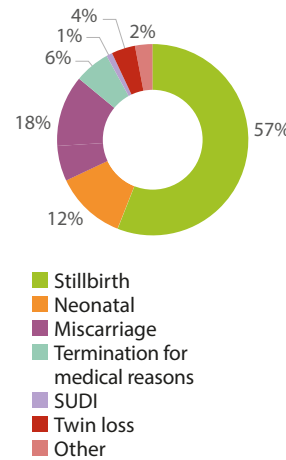
8% of calls and emails to the helpline are from parents whose babies died more than 20 years ago. This demonstrates the lack of care and support back then

“Thanks for listening. I needed that tonight.”
a bereaved mum after the neonatal death of her baby

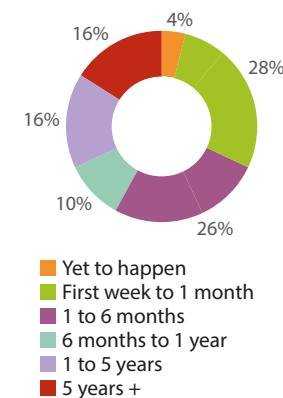
Who we've helped



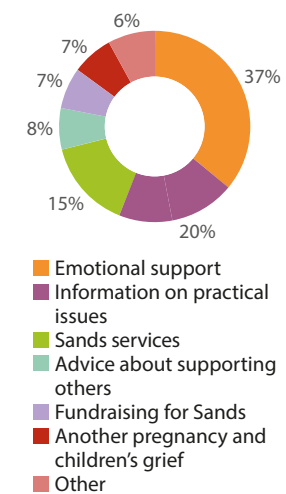
Nature of bereavement



How long after bereavement



Main themes of conversation



“Thank you so much. I have never had someone who understands my grief so well. It was as if you were beside me.”
a bereaved mum whose baby was stillborn

“Sands have been so supportive, we just wanted to speak to someone who knew what we were going through. Thank you.”
a dad bereaved after late miscarriage

“I'm surprised that I felt I could open up. I felt I could say anything without being judged.”
a bereaved grandma whose grandchild was stillborn

Online community

Many bereaved parents tell us that when a baby died they felt isolated.

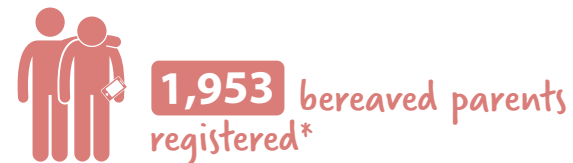
Our online community provides a safe space for bereaved parents to find information, share their feelings, connect and support each other 24 hours a day.

As well as supporting bereaved parents, the online community is available to other family members.



DID YOU KNOW?

Our online community was launched in 2005 and re-launched in 2017, when new features such as mentions, likes, groups and private messaging were added to enhance the community experience and support bereaved parents and their families.



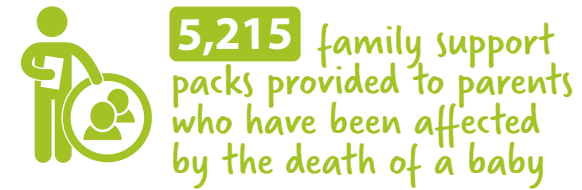
*Since re-launch in 2017

FIRST BEREAVEMENT SUPPORT BOOKLET

In 1986, we published our first two booklets: *Saying Goodbye to Your Baby* and *After stillbirth and neonatal death – what happens next*. In 1989, we produced leaflets *About other children*, *Loss of a grandchild*, *Next pregnancy* and *Facts for students*. *When A Baby Dies Before Labour Begins* was published in 1991. The booklets have been updated and newer editions published in 2003, 2010, 2011 and 2016.



Bereavement support materials



“For me, Sands means understanding and availability of support and information at the hardest time of our life so far.”
Shona

Memory boxes

We're working to ensure that every parent receives a memory box. Our memory boxes are free and contain a hand-knitted blanket, two teddy bears, *Always Loved Never Forgotten* card, support leaflets, a kit to take imprints of their baby's hand and foot, and other keepsakes.



“Sands provided irreplaceable memories of my unforgettable baby girl. My memory box, teddy bear and inkless prints mean the world to me. Thank you Sands for showing me I wasn't alone and for helping me to remember my precious daughter.”
Danielle

MEMORY BOXES

In 2009, Sands launched *Always Loved Never Forgotten* memory boxes following extensive research. In 2017 Sands memory boxes were made free for hospitals. They have always been free for bereaved parents and we have removed fees associated with hospitals ordering them in bulk.

Remembrance events

We hold two bereavement support memorial events each year – the Sands Garden Event and Lights of Love. Both events are for bereaved parents and families to remember their baby and to celebrate their lives. Both events are free to attend and are made up of readings, musical performances, and offer a chance for quiet reflection.

Sands Garden Event



400

bereaved families
attended from
around the UK

Where: The National Memorial Arboretum, Staffordshire

When: During Sands Awareness Month, early June

FIRST SANDS GARDEN EVENT

The Sands Garden Event was launched with a service at Lichfield Cathedral in Staffordshire in 2000.



Just writing this message brings a warm feeling to me and how special the evening always is. I am very grateful that you provide this service. It is a time I can just forget about the rest of the world and focus on my daughter.

a bereaved dad about Sands
Lights of Love service



Lights of Love



2,500

bereaved families
attended across
all 17 events

Where: London and 16 other locations around the UK, hosted by our support groups

When: Early December

FIRST LIGHTS OF LOVE

In 2004, the First Lights of Love service was held in St Paul's Church in Knightsbridge, London. Along with carols and readings, the Christmas tree was covered with cards bearing messages dedicated to a babies and loved ones who had died. This poignant event has been repeated every year since and is now held at many venues around the country.

STRATEGIC
OBJECTIVE
3





To grow as one strong,
sustainable and effective
organisation

We are working to ensure a sustainable financial base with diverse income streams, including developing individual fundraising opportunities and evolving corporate fundraising opportunities.



FUNDRAISING

Challenge events: London Marathon

	Raised	Runners
2015	£68,646	54 
2016	£100,000	72 
2017	£128,998	47 
2018	£94,851	45 

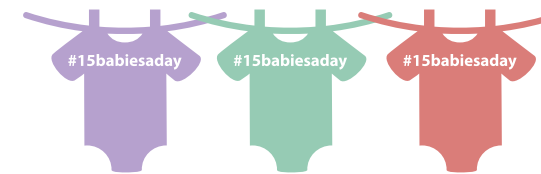


I ran both the 2017 and 2018 London Marathon for Sands. They were both as vital and valuable in raising money and more importantly awareness for the charity. It was an incredibly proud moment for me to be able to run in memory of my sister's baby Evan and for all babies that sadly die before, during or shortly after birth. Showing the world that they are not forgotten was an extremely powerful experience.

Chris



Sands Awareness Month



#15babiesaday campaign in June raised national awareness of the numbers of babies who die each day in the UK. Awareness raising washing line events were organised by volunteers and staff across the country.



It was hard hitting, but very powerful and visual.

Sands Volunteer



9,000+ views of campaign pages

18,150+ website views on 15 case studies pages

1,200 new followers on Facebook and Twitter

56 mentions in media

£5,300 raised by 10 fundraisers and 71 direct donors

£2,000 generated by Text2Donate 

#Challenge15



#Challenge15 is a new fundraising campaign, encouraging everyone to cover 15 miles, either cycling, running or jogging. We aimed to raise £15,000 to help reduce baby loss.

2,399 donations
£20 average donation.



£49,100
raised



61% of income came from new supporters

133 fundraisers
£366 average raised per fundraiser.

13% of supporters that took part have been fundraising for Sands more than 5 years

Christmas campaign: Gift of Support

The death of a loved and much wanted baby is devastating at any time of the year, but perhaps even more so at Christmas. The thought of Christmas can be anything but a celebration for anyone whose baby has tragically died. We wanted to highlight that potentially in December over 450 babies would be born and would not go home for Christmas.



104,278
people reached online

£16,462 raised by 344 supporters and 8 fundraisers

£1,877 generated by Text2Donate 

173 donations, **£9.78** average donation




£4,280 raised by Virtual Christmas Tree
27,500 views
414 donations
422 messages left
£8.70 average donation

CORPORATE PARTNERS

Companies play a vital role in helping Sands to continue to support anyone affected by the death of a baby and to raise awareness about baby loss.

Corporate and Trust fundraising is a relatively new function at Sands – our first corporate fundraiser was employed in 2015 and since then we have worked hard to grow our corporate income.

 **£300,000**
raised from the companies
in 2017/18

 **£135,000**
raised by our incredible
partners who chose Sands
as their Charity of the Year

 **£40,000**
raised from Trusts
and Foundations


Choosing to support Sands provides a fantastic opportunity to engage your customers and employees whilst supporting our vital work. 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.

We are incredibly grateful to all the companies, Trusts and Foundations that supported Sands in 2017, with particular thanks to the following:

Aldermore Bank Plc
Alliance Pharmaceuticals
ASCO UK Ltd
Charles Russell Speechlys LLP
Consort Medical Plc
The Cook Charitable Trust
Dawson Hinds
The Dullatur Foundation
The Fertility Partnership
The Hasluck Charitable Trust
Haysmacintyre
Homeserve
Horizon Discovery
The Sir James Reckitt Charity
The JC & KC Foundation
Mrs M A Black Charitable Trust
Marks & Spencer International Franchise Group
My Sales My Lets
NES Healthcare
QBE Foundation
Quartet Community Foundation
RAF Boulmer
RAF Shawbury
Rogers Stirk Harbour & Partners Charitable Foundation
Sainsbury's Food Commercial Division
Teddy's Wish
TK Maxx Foundation
Turtle Tots Scotland
Virgin Atlantic Airways (Virgineers Golf Society)

Alliance Pharmaceuticals go the distance!

Alliance Pharmaceuticals chose Sands as their Charity of the Year partner after staff nominated and voted for us. After our Corporate Fundraiser visited their offices to give a presentation about our work, they increased the target to highlight that every year in the UK, 15 babies die shortly before, during or soon after birth.

 **£12,500 original fundraising target**
£15,000 new target
£30,000 raised

To help them achieve this ambitious target, employees 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.



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.

John Dawson, CEO, Alliance Pharmaceuticals

Many thanks to all our corporate partners!

ASCO UK give their fundraising a golfing boost



ASCO UK chose Sands as one of their three chosen charity of the year partners in 2017 after several employees had experienced baby loss. The company celebrated their 50th Anniversary that year and their dedicated volunteer Lifestyle Team organised a variety of events throughout the year to help their staff and clients get involved with fundraising. This included a charity golf day at Newmachar Golf Club in Aberdeenshire and in spite of wet weather, more than 50 clients, suppliers and colleagues enjoyed playing in teams of three, with clients sponsoring holes for the day. The incredible enthusiasm and fundraising efforts of ASCO staff over the year helped to raise a fantastic £15,000 for Sands!





STRATEGIC OBJECTIVE
4

To raise awareness of the issues relating to stillbirth and neonatal death

COMMUNICATIONS

Creating hope online and breaking the silence

Digital channels create more ways for people to find and offer support on their own terms. We've expanded our online information materials and focused on appealing to the widest possible audience.

To raise awareness of the magnitude of baby death in the UK, we are continuously developing campaigns focused on breaking the silence with support of our ambassadors and a variety of communications channels.

We made great strides through our digital engagement work. Our traditional and social media reach continues to grow and engage wide and diverse audiences.

OUR FIRST WEBSITE

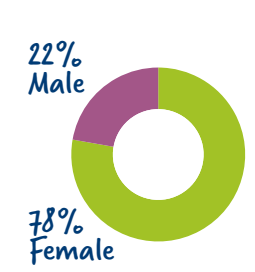
Sands launched its first website in 2003, which has proven to be an enormously useful source of support and information for many. The website was relaunched with a new look, better navigation, and most importantly key information and resources that Sands parents and members need.

Website visits



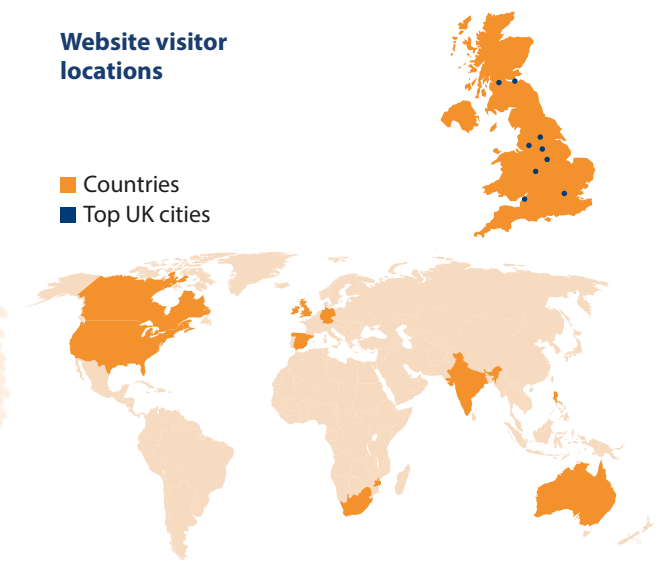
371,418
2017/18

17%
increase



Website visitor locations

■ Countries
■ Top UK cities

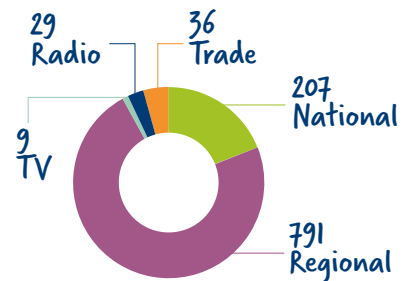


Media coverage

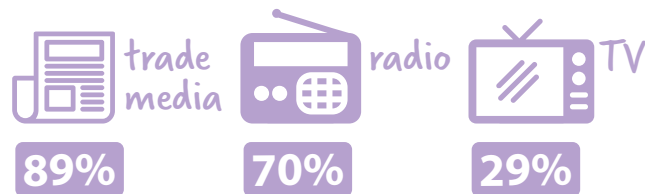


We were mentioned 1,082 times in online and print media, TV and radio, raising awareness of stillbirth and neonatal death.

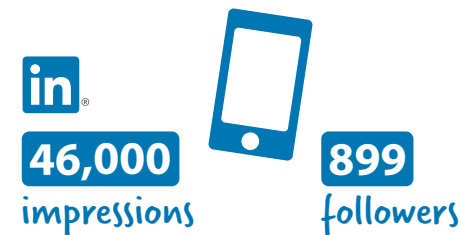
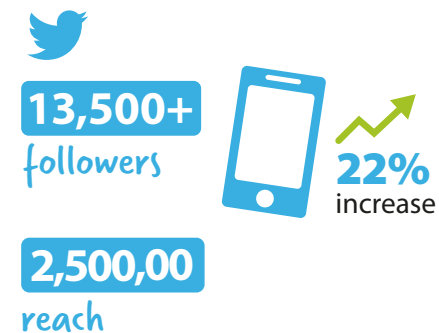
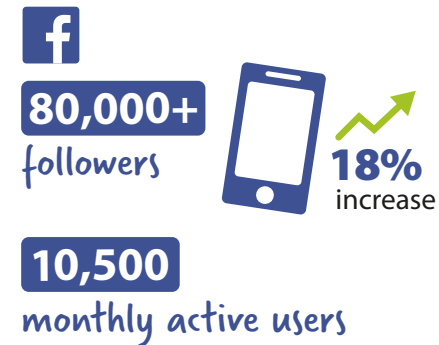
We were also increasingly asked to comment on stillbirth and neonatal death rates across the UK, as well as how to improve bereavement care and support.



Increase in mentions in 2017/18 compared to 2016/17:



Social media



BREAKING DOWN BARRIERS

Ambassadors

Our celebrity ambassadors support our vision to create a world where fewer babies die by promoting our work, speaking out about stillbirth and neonatal death and encouraging more people to support Sands. They are committed to our cause and to raising awareness of issues relating to stillbirth and neonatal death.

Our ambassadors:

- Rakhee Thakrar, actress
- David Haig MBE, actor, writer
- Matt Allwright, TV presenter, journalist, musician

Sharing stories

Many parents, families and professionals affected by the death of a baby shared their stories and their experiences with us. We published **23 stories** and **58 blogs** on a variety of issues surrounding stillbirth and the death of a baby to help other bereaved parents to feel less isolated and to raise awareness.

Stillbirth caused me isolation, heartbreak and unbearable pain
 Anyone who has experienced this understands the same
 Needing the understanding is so crucial to heal the heart
 Discussing my story over and over was the way to start
 Sands my lifeline!
 Hayley

The one thing I've learned... is that the most curative and reassuring thing is to unite with other parents who have been through the same tragedy.
 David Haig

I learned about Sands 3 years ago during our stillbirth storyline on EastEnders. Hearing about the devastation, grief and lifelong impact the death of a baby has on a family- I came to realise Sands truly is a lifeline.
 Rakhee Thakrar

DID YOU KNOW?

We've gathered 40 stories from long-ago bereaved parents as part of our 40th anniversary. These stories are very powerful and help raise awareness of baby loss and the ongoing support that Sands provides to anyone affected by the death of a baby over the decades. To learn more, visit sands.org.uk/40stories

CREATING OPPORTUNITIES FOR COLLABORATION

We're actively seeking opportunities for collaboration with other organisations. Developing and maintaining partnerships with baby loss charities and other organisations who work with bereaved families has remained important.

Baby Loss Awareness Week

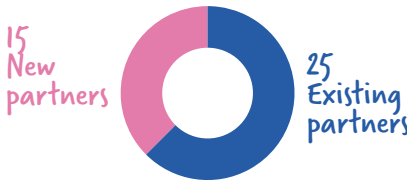


Our continuing collaboration that saw more than 40 charities come together in support of the week. Baby Loss Awareness Week aims to raise awareness about the issues surrounding pregnancy and baby loss. It is also a dedicated time to commemorate the babies who died during pregnancy, at or soon after birth and in infancy.

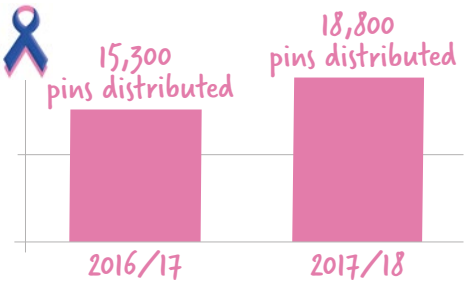
When: 9-15 October

Where: across the UK and Ireland

www.babyloss-awareness.org



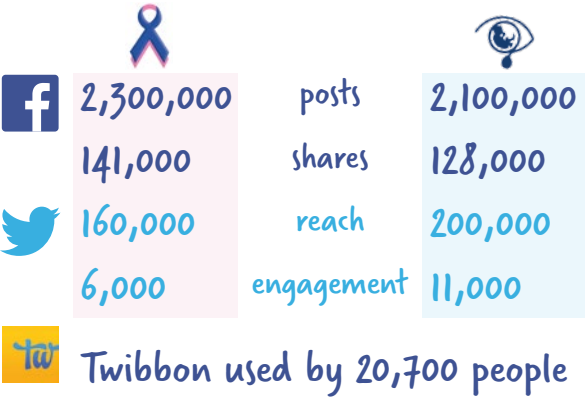
71 known events across the UK



LAUNCH OF BABY LOSS AWARENESS WEEK

The inaugural Baby Loss Awareness Day took place on 15th October 2002 uniting parents and families across the UK who have been touched by the death of a baby during pregnancy or just after birth. Inspired by Pregnancy & Infant Loss Remembrance Day in the US, the week was initiated by bereaved parents who had came together raising awareness and vital funds for organisations that support bereaved parents.

Social media reach



71 buildings and landmarks lit up pink and blue



Top to bottom: The Kelpies, Belfast City Hall, Merthyr Town Hall, Ely Cathedral and Refuge Tower Isle of Man.

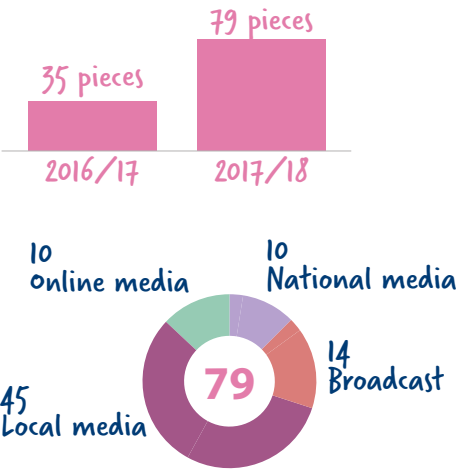
Wave of Light



On Facebook, we live-streamed our candle for an hour from 7pm on 15th October 2017.

346,000 views of the live stream
1.18 million people reached
700 photos of candles received
#WaveofLight trended on Twitter
151 virtual candles lit

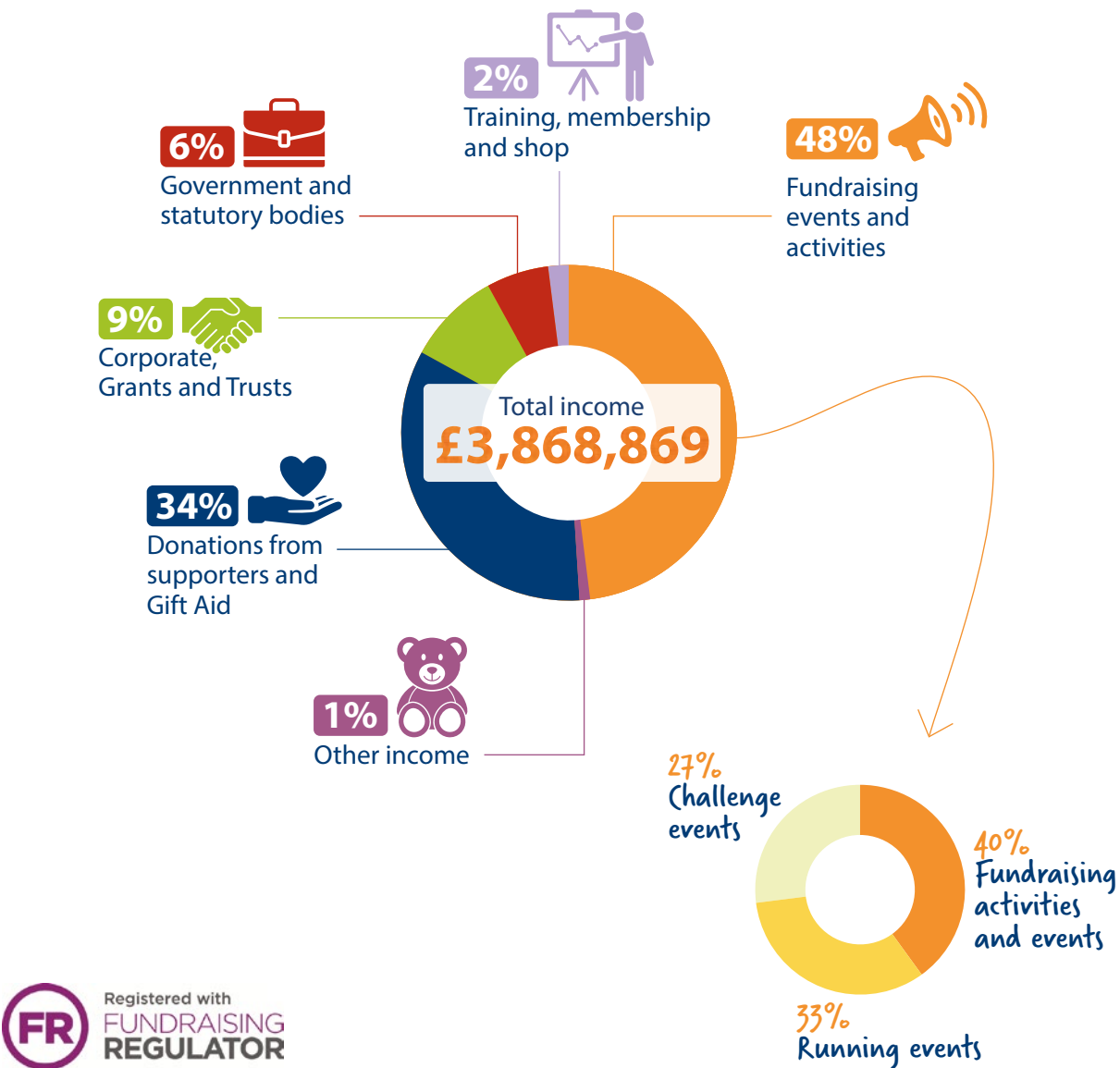
Media coverage



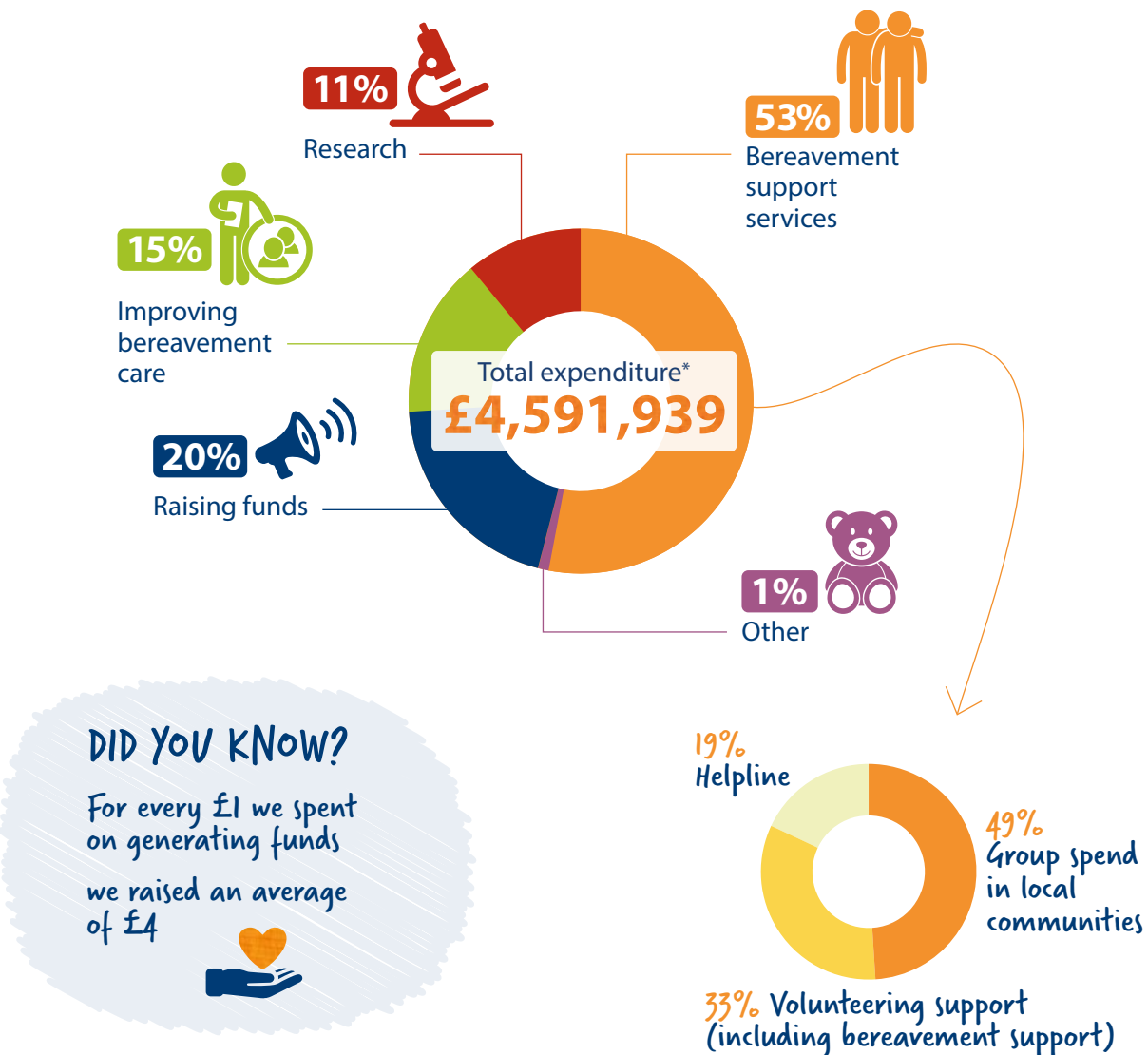
The main media highlight was Prime Minister Theresa May mentioning Sands, Baby Loss Awareness Week and the National Bereavement Care Pathway during Prime Minister's Questions on 11 October 2017 and many politicians wearing the ribbon pin badge.

OUR FINANCES 2017/18

How we raised our money



How we spent your money



*includes future funding commitments of £359,573



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w: sands.org.uk

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Support

t: 0808 164 3332

e: helpline@sands.org.uk

Sands online community

www.sands.community

Sands bereavement support app

www.sands.org.uk/app



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Supporting bereaved parents,
saving babies' lives

