



2018 - 2019

Impact Report



Welcome



Clea Harmer
Chief Executive, Sands

Following the many successes of this past year, it is important both to celebrate our achievements and to look forward to what more needs to be done in the future.

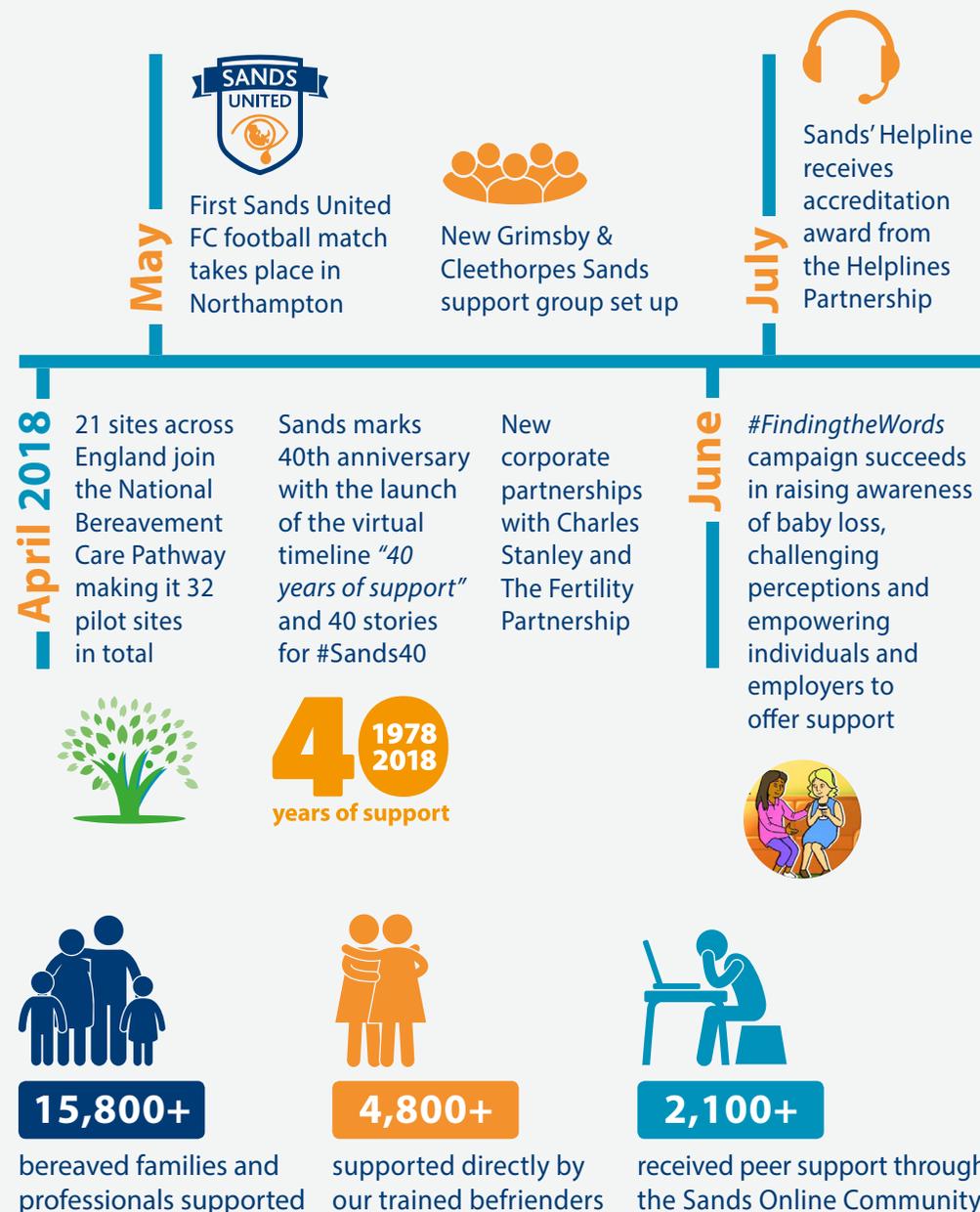
This impact report clearly shows our progress towards our vision.

I am so grateful to everyone who has helped to make a difference; your support and involvement is so inspiring. Thank you so much.

Our vision is for a world where fewer babies die and when a baby does die, anyone affected receives the best possible care and support for as long as it is needed.

If you'd like to learn more about the impact of our work and the difference your support makes visit sands.org.uk/impact2019

Our year at a glance





New parliamentary Act introduces a minimum of two weeks' leave for employees whose baby or child has died

September



Two new bereavement suites open, one at Northwick Park Hospital and one at Arrowe Park Hospital



New West Suffolk Sands support group set up



New Sands Bereavement Support App launches with almost 4,000 downloads in the first year

August

Sands agrees to fund new research studies to explore how pregnant women use digital resources to identify problems and to look at the cost effectiveness of care packages



October

With 60+ charity partners on board, *Baby Loss Awareness Week* secures Government commitments to improve bereavement care. Marks & Spencer join as the first corporate partner



November

New Plymouth Sands support group set up



Nex Group plc donates £50,000

January 2019

The NHS Long Term Plan commits to the national ambition to halve the rate of perinatal deaths by 2025



New Scunthorpe Sands support group set up

BRIT Insurance donates £10,000



February

Sam Kitson writes *In the Stars* in memory of her firstborn baby daughter Kitty. The picture book explores the death of a baby for younger children

Sands 40th anniversary conference *Past, Present and Future* is held in Glasgow with a special awards ceremony for 40 volunteers

March

NHS England publishes latest *Saving Babies' Lives Care Bundle* including Sands' safer pregnancy messages



Sands funded research leads to a new intervention to help identify stillbirth risk for pregnant women with a common liver condition



5,100+

contacted our helpline



3,800+

parents accessed information through Sands Bereavement Support App



2,000,000

people reached through our website, online resources and social media



270,300+

parents, family members and friends accessed bereavement support information and resources online



27,800+

healthcare professionals accessed Sands bereavement care resources

Our strategy 2017-2020

Everything you'll see in this report – the support we provide, the training we run, the research we fund and the way we raise money – is focused around our vision and three aims. We have four objectives to realise our vision and six commitments.



- Three aims
- Four objectives
- Six commitments

Government targets to reduce stillbirths and neonatal deaths*



England

reduce by 20% by 2020
and 50% by 2025

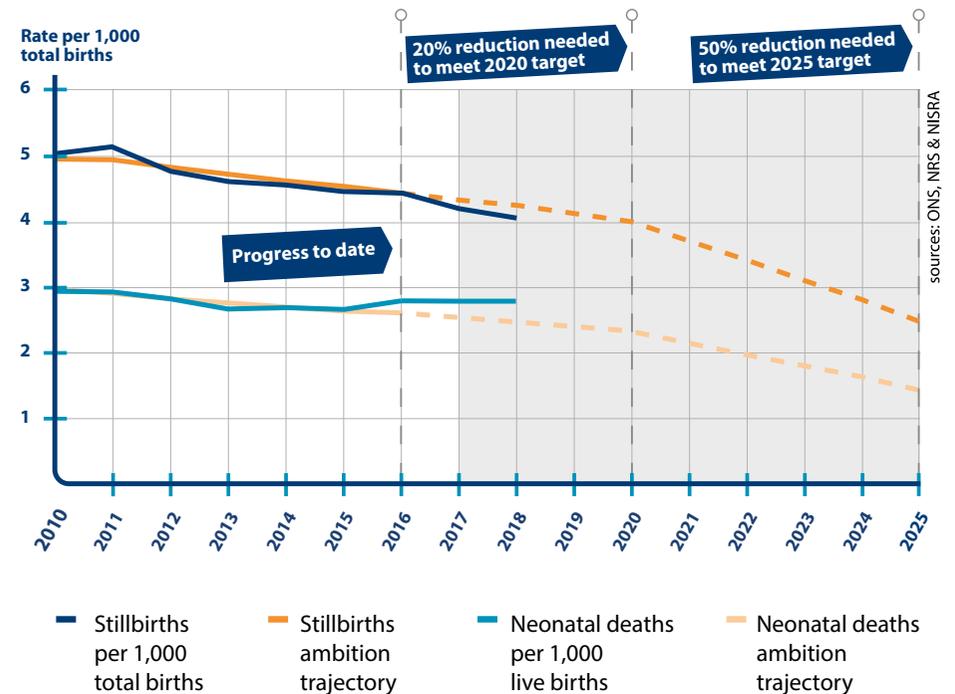


Scotland

reduce by 15% by 2015
and 35% by 2020

*Northern Ireland and Wales have no set targets

UK stillbirth and neonatal mortality rates (2010-2018) and National Maternity Safety Ambition trajectories.



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

7
live projects



2
new awards



In the UK, 15 babies die every day, before, during or shortly after birth. That's 3,200 stillbirths and 2,131 neonatal deaths in 2017*, similar to the previous year.



15

babies die every day

Major new initiatives to improve maternity and neonatal care have been introduced, alongside the national ambition to cut deaths by 20% by 2020 and 50% by 2025. While a fall in deaths is anticipated it's likely to be a few years before the initiatives result in a meaningful reduction.

Learning from research is vital if we are to achieve a significant and sustained reduction in baby deaths.

We need to know more about why many babies die and develop new treatments to prevent these deaths.

Sands has continued to identify and support high quality research projects that advance understanding of why babies die. For example, new research, part-funded by us, has revealed that women who develop diabetes in pregnancy which is not diagnosed, are much more likely to experience stillbirth. This increased risk can virtually be eliminated if the appropriate national guidelines for screening and diagnosis are followed.

Our work to support world class research helps to fill knowledge gaps, drive improvements in maternity and neonatal care and sustain the political will to reduce the number of baby deaths.

sands.org.uk/our-work

Sands Research Fund

What have we funded?

Side-sleeping

New advice that the risk of stillbirth is reduced if women in the last third of pregnancy go to sleep on their side.

Economic costs

Estimating the economic and social cost of stillbirth to families and society as a whole.

Third trimester ultrasound

Ultrasound scan measurements at the end of high risk pregnancies that predict if a woman is at risk of stillbirth.

Mortality reviews

How to support parents in communicating with and involving parents in a review of the baby's death.

Bereavement care

Evidence for what good bereavement care looks like.

Intrahepatic cholestasis

Getting the best management possible for pregnancies with ICP (intrahepatic cholestasis).

Fetal movements

Testing a package of care for pregnant women who report changes in their baby's movements.

Post mortem data

A new system for collecting information on post-mortem that could improve our understanding of why babies are stillborn.



Learn more about the studies we fund
sands.org.uk/research

Working to make maternity and neonatal care safer across the UK

Sands is helping to ensure there are robust reviews of every baby's death to learn lessons. This will help us improve care and give parents answers about why their baby died. By offering practical help to Trusts and Health Boards, we aim to make sure parent's voices are part of the review of their baby's death.



Sands has been involved in developing a range of parent engagement resources for the Perinatal Mortality Review Tool (PMRT), as well as working with the Healthcare Investigation Branch (HSIB) in England, and Serious Adverse Incident Review process in Scotland.



Following joint influencing by Sands and key policy coalitions, the NHS Long Term Plan published in January has a strong focus on maternity safety and a re-commitment to the national ambition to halve the rate of perinatal deaths by 2025.



Our safer and healthier pregnancy messages (based on the [Safer Pregnancy website](#)) were included in the revised Saving Babies Lives Care Bundle published by NHS England. All Trusts in England are incentivised to follow this national guidance.



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

Compassionate, sensitive, family centred bereavement care can have a significant impact on the wellbeing of families in both the short and long term. Good quality care provides families with the opportunity to grieve safely and may contribute to the prevention of conditions such as PTSD, anxiety and depression.

It is recognised that bereavement care in the UK has improved in recent years, with some parents saying that they received excellent care. Unfortunately, this is not always the case and bereavement care across the UK remains patchy. This inconsistency is seen across healthcare providers and also between different types of loss. Sands passionately believes that all bereaved parents should have access to high quality, sensitive and individualised care, regardless of

circumstance, gestation or post-code. It's for this reason that Sands actively works with health care professionals to ensure they are equipped and able to deliver the best possible care.

Sands continues to deliver bereavement care workshops for health care professionals across the UK. Our curriculum has recently expanded and we are now in a position to deliver training for a variety of professions including midwives, nurses, students, doctors, health visitors, doulas, counsellors and interpreters.

This year we facilitated training workshops at 145 locations across the UK and feedback from attendees was excellent



"Brilliant training, really helpful. I now feel much more confident in caring for these families."
Midwife

sands.org.uk/training



national bereavement
care pathway
for pregnancy and baby loss

The National Bereavement Care Pathway (NBCP), seeks to improve the quality and consistency of bereavement care received by parents from the NHS after pregnancy or baby loss.

Sands leads the government backed National Bereavement Care Pathway (NBCP) in collaboration with bereaved families, other charities and Royal Colleges, which provides health care professionals with frameworks, tools and educational resources to

support excellent care. The NBCP is based around nine standards of bereavement care and includes pathways for miscarriage, termination of pregnancy for foetal anomaly, stillbirth, neonatal death and sudden unexpected death of an infant up to 12 months.



For more information on the NBCP, including access to resources and tools please visit nbcpathway.org.uk

From October 2017 11 NHS Trusts piloted the NBCP in England and in April 2018 and a further 21 Trusts joined the programme. The NBCP is now being expanded into Scotland. The plan for the coming year

32 
Trusts in England have adopted the NBCP

An independent evaluation concluded that the NBCP is having a positive impact.



The proportion of professionals feeling prepared to communicate with bereaved parents increased



The proportion of professionals feeling supported to deliver good quality bereavement care increased

is to improve access to our educational resources and to embed the NBCP so that health care professionals across the UK are equipped and able to provide excellent bereavement care.

"I truly hope this becomes a national standard that all bereaved parents will benefit from, as I cannot express how much it has helped us navigate through this most difficult time."
Parent

Volunteering at Sands

2018 was an amazing year for our volunteers.
We are so proud of them and the work they do.

Offering peer support

4,800+



parents and families supported last year by our trained, dedicated befrienders

107+



support meetings run each month

Sands' peer support meetings are a lifeline for parents. The company of other bereaved families, and the skilled facilitation of our befrienders, creates a safe space for parents to talk about their baby, perhaps for the first time. It is a place where they can acknowledge their grief, discuss their feelings, and start on the path to building a new normal, after experiencing barely imaginable loss.

Improving bereavement care

2



hospitals complete major bereavement suite projects with the help of Sands volunteers

Uniquely, Sands volunteers and supporters project the voice of bereaved parents, giving insights into good bereavement care based on direct experience.

Well-designed bereavement suites give parents a calm, appropriate space to make memories with their babies while in hospital. Equipment such as cuddle cots was also donated to hospitals following fundraising by our volunteers and supporters.

"The Way to find much needed information. To meet local people who understood. To give something back, improve care and make a short life meaningful long term. To remember my beautiful son, Evan, for nearly 30 years."

Wendy

Memorial events

A memorial event allows those who have experienced the death of a baby to remember and say their names out loud among others who understand what that means.

Our wonderful volunteers allow families around the country to mark special occasions with thoughtfully curated memorial events: family picnics in the summer, Wave of Light events during Baby Loss Awareness Week, Lights of Love services at Christmas, plus further services (including non-religious events) across the year to include Easter, Mother's Day, and Father's Day.

Sometimes an event is as simple as a walk in the park, to talk and remember. It could be having the chance to light a candle, write a name on a stone, or place a flower in the stream. Our volunteers support bereaved families in a variety of ways, not only those who befriend, but those who organise the events, or fundraise to support them. If you want to learn more, please visit sands.org.uk/volunteers.

Thanks to our inspiring volunteers there are now four new or updated memorial spaces in Bristol, Cardiff, Wrexham, and Oxford. Here parents and families can sit, reflect, and remember their baby in a dedicated space.



Bereavement Support

We aim to support bereaved families where they are and when they need us

4,800+



bereaved parents and families supported directly by our trained befrienders

2,100+



bereaved parents joined the Sands Online Community

49,000+



visits to the Online Community made using mobile phones

2



bereavement suites opened

53%



contacts to our helpline were from recently bereaved parents

4



memorial gardens opened

"I've called this helpline several times after my daughter died in January. The people I've spoken to have been amazing. They've helped me through the darkest moments of my life. They couldn't be more supportive, knowledgeable. They know what to say and what not to say. Thanks for helping me survive the darkest of days."

Learn more about ways we offer support at sands.org.uk/support

Bereavement Support App

The Sands Bereavement Support App was created to help bereaved parents and families to find the right information and support at the right time.

The idea to create an app was inspired by Nicole Regan-White, a bereaved mother, whose baby Jessica was stillborn after 42 weeks gestation on 24 December 2013.

"Shortly after we lost Jessica I contacted Sands to let them know that searching for information was difficult and overwhelming for bereaved parents at the time of a baby's death."

"In a digital age we discussed my idea of creating an app that can be downloaded in seconds that provides all the information a bereaved parent and their family would need anytime, anywhere."
Nicole



The app can also be used by healthcare professionals, who would like to know how best to support bereaved parents and their families.



2,500+

iOS downloads



1,300+

Android downloads

"Invaluable."
Bereaved Mother

"So pleased to see this valuable resource launched."
Influencer



Learn more and download the app at sands.org.uk/app

Bereavement Support Book

Throughout the year we worked to update the Sands Family Support Pack to a fresher, more up to date look and to include additional information on:

- Ages and stages of children's grief
- Support for those who do not have children following loss
- More diverse images and language to appeal to a wider range of bereaved parents



The Bereavement Support Services team was supported by health care professionals, bereaved parents, volunteers and staff in reviewing and editing drafts. Parents were invited to share their own photographs for inclusion within the book, which enabled us to show images from a diverse range of parents including Black and Asian parents and same-sex couples and to reduce anxiety from parents contacting our team about "what to expect" when their baby is born.

The book will be easier to store in hospitals and can also be given with non-Sands memory boxes more easily than the previous large pack.

All bereaved parents should have access to high quality, sensitive and individualised care regardless of circumstance, gestation or postcode

Order a copy today or read online at sands.org.uk/book



Remembrance events

Our Remembrance events ensure they allow room for hope and growth as well as special time to remember babies who have died. This is following feedback from parents who wanted to leave events feeling that they had the time they needed but also left feeling uplifted, positive and supported for the future. We have been discussing this at our Sands Days around the UK to ensure that development of Sands Group events and fundraising activities follow this growth model of bereavement, at the same time as creating opportunities to continue parents' positive bonds with babies who have died.



Support themes

We have been looking at areas of support which are currently less well provided for, including sibling support and support for those at significantly higher risk of stillbirth and neonatal death e.g. Black and Asian women, to plan our work for the next year. We have also started to plan more resources for those bereaved neo-natally; working with a clinical psychologist and bereaved parents.



Access to our services

We have broadened our Bereavement Support Team remit to include wider social media support and regional initiatives such as workshops alongside plays, advising on TV storylines and our first input into a primary school. This will all help inform our resources for siblings and children and also the development of support for men and minority groups at higher risk.



Surviving and thriving through grief

We have developed increased safeguarding provision in the Bereavement Support Services team and support for those at a really vulnerable point in their grief. We know that talking with bereaved parents about the common but sometimes frightening emotions and anxieties following the death of a baby can enable their grief to be less isolating and enabling them to reach out more easily for wider support at Sands Groups or with family and friends.

To grow as one strong, sustainable and effective organisation

Together we have achieved so much since Sands was founded by two bereaved parents in 1978

Sands continues to grow as one strong organisation, with a real focus on building both the culture needed to form the foundation for 'one Sands', and also the processes and policies that will support this way of working.



By the end of 2018/2019 all Sands Groups had moved into a single banking structure, a significant achievement for those involved, and a real cornerstone for working as a single organisation going forward.

2018 marks 40 years since Sands was founded by two bereaved mothers, Hazelanne Lewis and Bel

4

1978
2018

years of support



Mooney. This year we were pleased to reconnect and welcome them as patron's. Our interactive timeline, 40 years of support, captured key achievements, honouring everyone who has worked with us. We've shared 40 stories from bereaved families to break the silence around baby loss and highlighted 40 amazing volunteers at a special awards ceremony.

#Sands40



To raise awareness on social media, we created a [digital toolkit](#) with suggested posts and images.

sands.org.uk/40years

Timeline 40 years of support



Our [interactive timeline](#), 40 years of support, captured key achievements, honouring everyone who has worked with us.

40 stories for #Sands40



Throughout 2018 we invited bereaved parents, family members and friends affected by the death of a baby to [share their stories](#) and [experiences of loss](#), including those who are long ago bereaved.

Anniversary Conference Sands' 40th



Past, Present and Future took place on 17 November 2018 in Glasgow. The event provided an opportunity for the whole organisation to come together, celebrate what has been achieved over the last 40 years and commit to what more needs to be done to make our vision a reality.

40 volunteers for #Sands40



Our volunteers are fantastic! We celebrated their brilliant achievements throughout 2018 by highlighting 40 of them. We also hosted a special volunteer awards ceremony in November. Find out who they are sands.org.uk/40volunteers.

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

We have improved our understanding of our audiences and their needs by taking an insight led, evidenced based approach to help inform our awareness raising activity and campaigns so that we are even more effective as the voice of bereaved parents.



1,200+ mentions across all types of media

#FindingTheWords campaign

The Sands Awareness Month *Finding the Words* campaign succeeded in raising awareness of the scale and scope of baby loss, challenging perceptions and empowering individuals.



10,000 times the animation was shared

f 1,900,000 people reached on Facebook

sands.org.uk/campaigns

Moving forward Sands has built strong relationships and connections both politically and with clinicians and researchers. It is important now to develop wider relationships with key influencers and opinion formers, especially with regard to younger age-groups. This will enable us to raise awareness of the issues around stillbirth and neonatal death more widely and to start to break the taboo.

"Sands are the reason I'm still here. Without their support I would have given up when my son was stillborn at 29 weeks. I now have my rainbow baby, and I'm still here to care for my 2 sunshine children. Thank you Sands."

Amy

Bereavement at Work

Many bereaved parents do not receive the support they feel they need from employers after the death of a baby.



2700+ bereaved parents, grandparents, and other family members responded to our survey, to find out whether they were supported in returning to work after the death of their baby.

After the death of their baby, people felt:

most supported by

family (7/10)

friends (6/10)

least supported by

employers (5/10)

wider community (3/10)

60% felt supported by their friends

50% felt supported by their employers

70% felt supported by their family

30% felt supported by the wider community

1 in 5 were aware of their employer's policies for supporting staff if their baby died

49% of employers did not discuss entitlements to pay and leave with people following the death of their baby.

Discover more at sands.org.uk/findingthewords

Sands led the political engagement aspects of Baby Loss Awareness Week 2018, briefing over 600 UK politicians with over 100 attending events or speaking during debates aimed at improving bereavement care.

In October, Baby Loss Awareness Week 2018 focused for a second year on improving bereavement care. This year the policy call was for implementation of the National Bereavement Care Path. The week was hugely successful helping more people than ever to commemorate their babies' lives, create change and raise awareness of baby loss.



Politicians across the UK gave public support

139 

Wave of Light and Ribbon Awareness events held

5 

events: 2 in Westminster, 1 in Scottish Parliament, 2 involving Welsh Assembly

169 

media coverage received

30 

new partners in 2018, and 40 existing partners

#waveoflight 

trended in top 10

25,000+ 

pins distributed

 **Baby Loss Awareness Week**
9-15 October
babyloss-awareness.org

180 buildings lit up pink and blue



In England, the Minister committed to writing to CQC to ask about integration of the National Bereavement Care Pathway into their inspection frameworks. In Wales, the Cabinet Secretary committed to reporting back on progress being made to improve bereavement care.

2,144,000  people reached on Facebook

1500  candle tins distributed

11,000  people reached on Instagram



249,000 views of first ever animation

516,000  Twitter impressions

Get involved and be part of Baby Loss Awareness Week 2020
babyloss-awareness.org

Support from companies is vital to help Sands raise awareness and to fund our important work and corporate fundraising remains a crucial area of growth for Sands.

We were enormously inspired by the outstanding fundraising efforts of all our partners and their employees who took part in a variety of activities; from bake sales, challenge events, charity golf days, skydives and even a Directors jailbreak!

£450,000

raised this year from organisations choosing to support Sands.

£50,000

Highlights included an incredible donation from Nex Group Plc following an employee nomination and a host of companies choosing Sands as their Charity of the Year partner.

Following the support they receive from Sands, bereaved parents, their family members, friends and colleagues are often motivated to nominate Sands to benefit from a corporate donation from their employer, either through matched funding

following a fundraising event or for a one-off donation.

In December 2018, Jackie Clarke's Granddaughter Ruby, was still-born at 41 weeks. Jackie worked for Brit Insurance and nominated Sands for a corporate donation.

"The loss of our beloved Ruby has left a hole in all of our hearts but without the support of our bereavement midwife and Sands we would not be able to get through this terrible time. Their support is invaluable and we hope these corporate donations can go to help other parents and families like it has for us."

Jackie

£10,000

We were fortunate enough to receive £10,000 and subsequently chosen as one of Brit Insurance's charity partners.

Ruby's mother, Leonie was also keen to see how her employer Liberty Global Group could help.

To find out how your company can support Sands, visit sands.org.uk/corporate-support

£5,000

received from Liberty Global Group following a nomination and application.

Our corporate fundraiser also supported a friend of the family who wanted to nominate Sands via her employer Avison Young and we are delighted to have very recently been awarded a grant.

£2,500

grant recently awarded by Avison Young Employee Community Fund.

£100,000

We are aiming to establish a robust portfolio of Trusts that raises in excess of £100k pa in unrestricted income by 2023/24 in addition to a restricted funding programme.

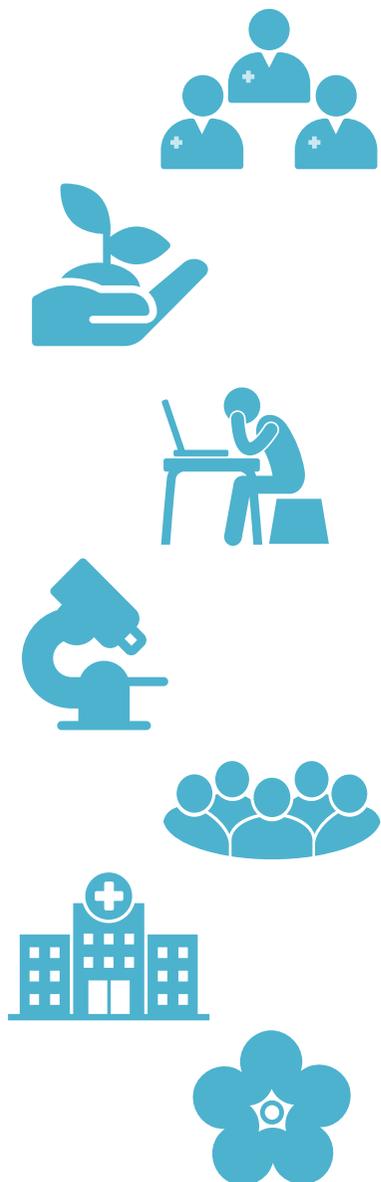
Fundraising from Trusts and Foundations continues to be a key area of growth enabling Sands to maintain and develop its work supporting bereaved families and those affected by baby loss and saving babies' lives.

We are incredibly grateful to all the companies, Trusts and Foundations that supported Sands in 2018, with particular thanks to the following:

NEX Group plc
Marks and Spencer plc
The Fertility Partnership
Hiscox Insurance
Stadco Ltd
Brit Insurance
Tozers Solicitors LLP
Institute of Cemetery & Crematorium Management (ICCM)
Lloyds Banking Group
Xperience Group
Aspect Capital
Teddy's Wish Ltd
Charles Stanley
Landsdowne Partners UK LLP
Liberty Global Group
Mumford and Sons Gentleman of the Road Fund
Artemis Charitable Foundation
Juditeras Charitable Trust
Lola Rose Foundation
Mrs M A Black Charitable Trust
The Sir James Reckitt Charity
Rugby Group Benevolent Fund
One Family Fund
Truemark Trust
Lincoln Spiritual Association
The Jessie Spencer Trust
The Macfarlane Charitable Trust
R S Brownless Charitable Trust
Yorkshire Building Society Charitable Foundation
Horizon Discovery
Turtle Tots
The Co-operative Group

To speak with our corporate partnerships team contact corporate.partnerships@sands.org.uk

Lessons learned



Research and prevention

Preventing baby deaths is central to everything Sands does, but we need to communicate more effectively about this core aspect of our work and better demonstrate the difference that we can make both to bereaved families now and to all families in the future.

Improving Bereavement Care

Standards of care are improving gradually, especially where bereavement midwives are employed. However, care remains inconsistent and there is a need for doctors and other staff to engage in bereavement care education and for Sands to widen our teaching methods. We have also learnt that employers need support to respond sensitively to staff who have experienced a pregnancy or baby loss. There's nothing like the parent

voice to bring about change as was highlighted through the work of the Parent Advisory Group and through the evaluation of the National Bereavement Care Pathway pilot sites.

Bereavement Support

We have been working to diversify the support we offer to serve the needs of all family members, including fathers and siblings. We want to reach out to families that are at higher risk of stillbirth and neonatal death, and offer variety of ways to support them.

Our support events ensure they allow room for hope and growth as well as special time to remember babies who have died. This is following feedback from parents who wanted to leave events feeling uplifted, positive and supported for the future.

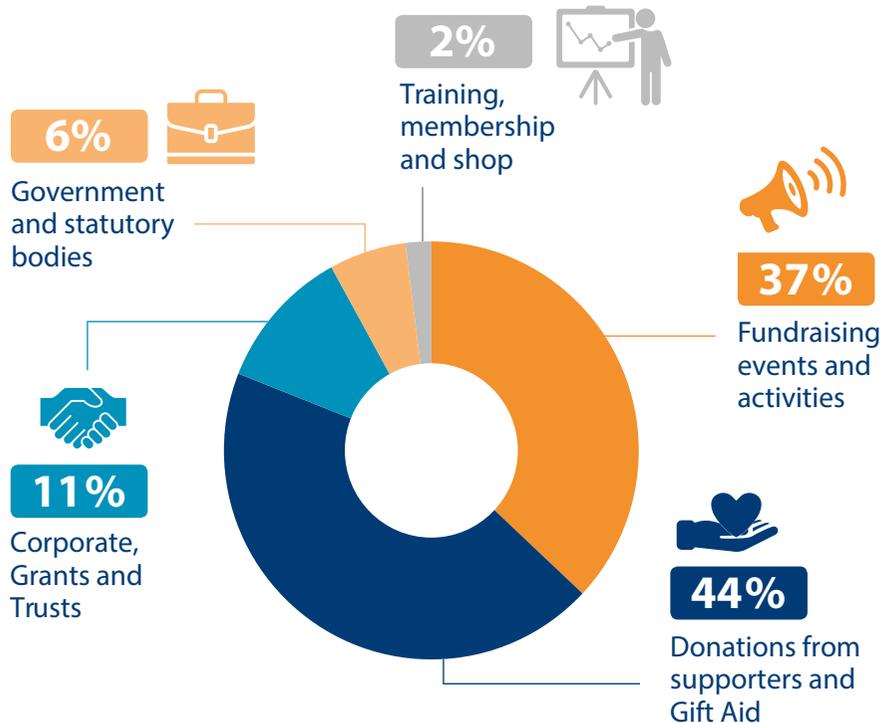


If you'd like to read more visit
sands.org.uk/impact2019

Our Finances

Total income

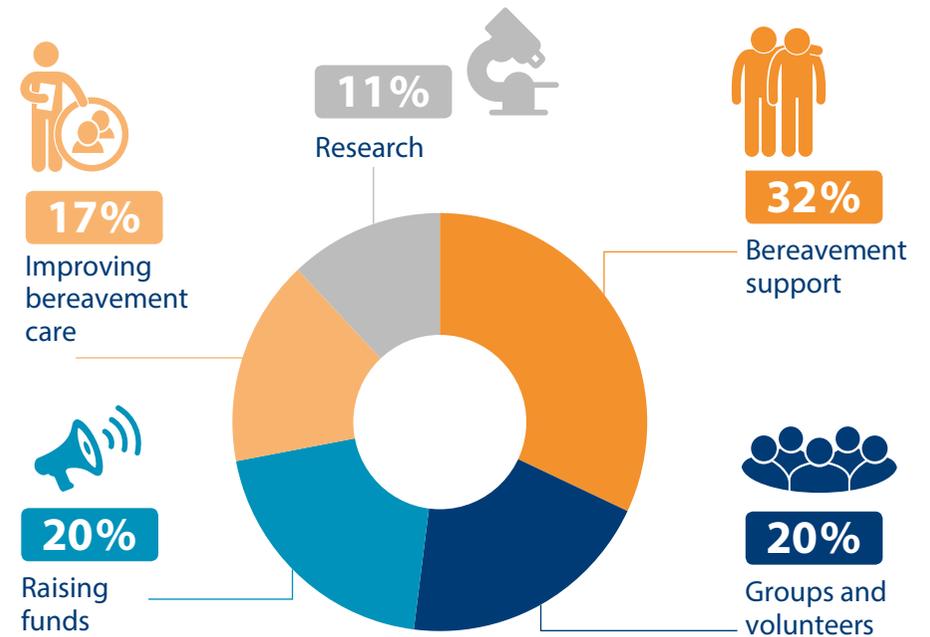
£4,115,329



Total expenditure

£4,311,083

For every £1 we spent on generating funds we arised an average of £4



We are determined to make a real difference to the lives of bereaved families across the UK. But we can only continue to deliver our crucial work with your support. When you donate or fundraise for Sands, you are supporting our vision of a world where fewer babies die and helping to ensure that every bereaved family, wherever they live in the UK, gets the care and support they need, when they need it, for as long as they need it.

To get involved
sands.org.uk/get-involved

To make a donation
sands.org.uk/donate

t: 020 7436 7940
e: info@sands.org.uk
w: sands.org.uk

Victoria Charity Centre
11 Belgrave Road
London
SW1V 1RB

To make a donation
sands.org.uk/donate

To get involved
sands.org.uk/get-involved

Support:

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

Online community:
sands.community

Sands bereavement support app:
sands.org.uk/app

Registered with



FUNDRAISING
REGULATOR

Charity registration number 299679. Company Limited by Guarantee Number 2212082 •
Scottish Charity Registration Number SC042789 • We also operate in Northern Ireland.