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.

Impact Report 2019 - 20

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Contents





Clea Harmer *Chief Executive, Sands*

ands has achieved much in the past year and this report is testament to the hard work and commitment of all our staff and volunteers, many of whom are bereaved parents themselves, and to the dedication of all our members and supporters without whom Sands simply would not exist.

Significantly during 2019 we saw a welcome fall in the UK's stillbirth rate. This followed concerted efforts by Sands to support key policy, safety and research initiatives across the UK, working in partnership with Governments, the NHS and decision-makers. However, there is no room for complacency. The fact remains that 14 babies a day in the UK are stillborn or die within four weeks of birth. We must redouble our efforts if we are to halve the number of baby deaths by 2025.

At the end of the period covered by this report the COVID-19 outbreak had already begun to affect families across the UK and we had already seen an increase in demand for our bereavement support services.

Despite the immense challenges that were on the horizon as we entered 2020, Sands continues to do everything possible to save babies' lives, and support anyone left shattered by the death of a baby.

Thank you so much.

Clea





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

Research & Prevention

- Identified four new research projects for grant awards, across a range of topics, following our AMRC-accredited peer-review selection process.
- Supported five Sands-funded research projects in our live research portfolio.
- Supported more than 12 additional research studies relevant to baby loss, including helping with study design, recruitment, patient information and dissemination.
- Worked with University College London to develop a training program for healthcare professionals, based on the findings of Sands' research, to improve communication with parents making difficult decisions about care for very sick newborns.
- Launched the Parent Engagement materials for the Perinatal Mortality Review Tool (PMRT) which is now being used by 100% of Trusts and Health Boards. The engagement resources are now available on our website and in Sands Training for professionals to help improve bereavement care. Our podcast about reviews has been welcomed Dr Mary Adams the co-lead on the DISCERN study (discernstudy.org), described it as "inspiring".
- The PMRT annual report mentioned the word parent more than 100 times and we wrote the Forward – an acknowledgement of our contribution from the start.
- Over 1500 parents responded to a survey about maternity and neonatal care. The findings informed the Baby Losst Awareness Week report and work to influence Government and NHS care provision.

Reducing deaths – a renewed need for Sands and the parents' voice

It's more important than ever that Sands is there to make sure parents' experiences are heard at national level. Falling stillbirth rates have become a new normal in recent years after decades when high mortality rates were overlooked. This is because parent groups, and particularly Sands, campaigned to make safety a priority for maternity care.

With a new focus on spotting babies at risk and better guidance for what action maternity professionals should take to prevent deaths, Sands has carried on being central to work to make sure these improvements continue and build.

Long experience has shown that the collective voice of bereaved parents is a powerful and crucial force to keep a focus on safety and make a difference to outcomes in the future.

Public Affairs and Campaigns

As a member of the Pregnancy and Baby Charities Network we got our pledge to "Make the UK the safest place in the world in which to have a baby" into the manifestos of the three main political parties for the 2019 general election. In March 2020 our Chief Executive Clea Harmer, visited 10 Downing Street alongside Judy Ledger, Chief Executive of Baby LifeLine, to present an open letter to Prime Minister, Boris Johnson that called on the Government to reinstate the Maternity Safety Training Fund to help to improve maternity safety.

In 2018

4,947 babies died

around

95
families were bereaved every week

One baby died every 106 minutes

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For every 150 births, one baby died

06 minutes

UK stillbirth and neonatal death rates per 1000 live births

Stillbirth Rate
Neonatal Death Rate



08 2009 2010 2011 2012 2013 2014 2015 2016 2017 201

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

National Bereavement Care Pathway (NBCP)

It is crucial that parents receive consistent high quality bereavement care appropriate to their needs and the NBCP sets out the standards so that parents feel supported on their bereavement journey.

With around half of hospital trusts in England adopting the NBCP, momentum is building and trusts already adopting the NBCP have reported tangible improvements and positive feedback from staff, parents and families.

An evaluation of the NBCP sites across England in May 2019 found that 76% of professionals who were aware of the pathway agreed that bereavement care improved in their trust during the period of the pilot. Parents also reported high levels of satisfaction with the bereavement care they received when their baby died.

For more information visit nbcpathway.org.uk

Improving Bereavement Care

We continue to work with healthcare professionals to ensure they are equipped and able to deliver the best possible bereavement care. This year our team of specialist trainers continued to deliver high quality workshops for healthcare professionals and the feedback from attendees was excellent.

Sands' volunteers helped 11 hospitals provide high-quality spaces where bereaved parents can make memories of their baby, while receiving the medical care they need. Through consulting on redevelopment plans, purchasing soft furnishings and other items to make the spaces less clinical, and funding equipment such as cold cots, Sands continues to help ensure that the extra support that parents need is available in their darkest moments. Sands is able to reflect back to hospitals the voice of bereaved parents, and the insights this can give, as well as our fundraising capability, is of great value to Trusts.

"A really useful, touching session that will definitely make me a more compassionate practitioner. Thank you"

workshop participant

"Really enjoyed the day, felt like I have learnt a lot and now feel more confident in caring for bereaved families. The speaker was very knowledgeable and made the day interesting and interactive"

workshop participant



face to face workshops delivered. 10 postponed due to Covid

2460 health care professionals trained



of paticipants would recomend our training

100% participants report feeling more confident in communicating sensitively and effectively with bereaved parents & their families



Bereavement in the Workplace

This year also saw the launch of Sands Consultancy, though which we support statutory, voluntary and corporate services on all issues relating to the death of a baby, ensuring that organisations and individuals have the knowledge, skills and confidence to work with the bereaved.

Paul Hay, Environment, Health and Safety Training Manager at Lendlease Europe, said:

"It's incredibly important for us as a company to support the wellbeing and mental health of all our employees. Ensuring we have the right support in place for anyone who has been affected by baby loss is a crucial part of our mental health programme and so it was imperative that we took part in these informative and expertly delivered training workshops from Sands"



Resources and Information

This year we published the Sands Bereavement Support Book, which replaced the Family Support Pack. This not only reduced our environmental impact but increased accessibility through broader representation of parents and families we support. A book review in the British Journal of Midwifery concluded:

"Overall, the book is an excellent resource for families at a time when guidance and support are essential. It is a holistic representation of the work that Sands does to provide a supportive network for parents and families at a tragic time in their lives."

(Lydia Baker, Bereavement Midwife)

We also redesigned the Sands Memory Box to complement the Bereavement Support Book. The Memory Box contains items designed to comfort and support bereaved parents now and in the future.

Public Affairs and Campaigns

170 MPs were sent a nation specific briefing including progress on bereavement care ahead of the Baby Loss Awareness Week 2019 parliamentary debate. In response to the debate the Minister committed to bereavement suites in all new hospitals in England. The Pregnancy and Baby Charities Network manifesto ask to provide every family with the bereavement care they need after pregnancy or baby loss was included in three main parties' manifestos for the 2019 general election.

In January we welcomed the Secretary of State for Business, Energy and Industrial Strategy, Andrea Leadsom MP to our offices to announce that the Parental Bereavement Leave and Pav Act Regulations would be laid before Parliament and come in to force in April. The Act ensures bereaved parents will have a right to at least two weeks paid leave from work in addition to their existing parental leave entitlement, including bereaved parents of babies stillborn after 24 weeks.

Sands United

Sands United Football Club (SU FC) continued to grow in strength across the UK to 31 teams with membership totaling over 400 players. Most recent additions to the Sands United family are Ashby, Exeter, Hereford, Huddersfield, London and Salisbury.

Prestigious awards won including the FA and McDonald's Grassroots Football Awards Club of the Year (SU FC Solent) and FA and McDonald's Grassroots Football Awards Project of the year 2020 (SU FC Hull & East Yorkshire and SU FC Stockport).

In May 2020 Sands United FC Northants were in the national media spotlight after their involvement in the BBC documentary Football, Prince William and Our Mental Health

Lives have been saved and transformed by Sands United FC, when men have found they are not alone as they grow around their grief.

"Although losing Thomas was devastating it's given me hundreds of brothers around the country who I can share a football pitch with. Hundreds of brothers who with just a look can say 'I feel your pain and I'm here for you'. Before Sands United FC many of us wouldn't necessarily have spoken much about our angels or said their names. As part of this national brotherhood I proudly carry Thomas' name on my shirt and am happy to talk about Thomas and Sands United at any time. The teams have been able to reach out to guys who wouldn't normally have spoken about their loss and for some the teams have bought them out of a very dark place and saved them"

Peter, SU FC Bristol.



400+ Sands United members

1,500+ accessed direct support from befrienders





5,000+ meeting attendees



Direct Support Services

Our Bereavement Support Team responded to 2,459 calls, 1,983 emails and over 100 requests for support via facebook during the year. Our Online Community continued to provide a safe, moderated space for peer support. Members shared just under 31,000 posts and 1,845 new members joined the community.

The Garden Day in June and Lights of Love services in December provided support and comfort to over 1600 families across the UK.

During February and March, we were able to adapt and continue our services in the light of Covid-19. We provided information and support to families faced with the restrictions and delays to funeral arrangements, post-mortems, and visiting graves as a result of Covid-19. The direct experiences of bereaved families and those pregnant after loss were used by our Research and Prevention colleagues to inform immediate changes in official guidance to working practices in order to best support bereaved families.

Groups and Volunteers

Our trained, dedicated befrienders ran more than 1.000 support meetings last year, with a total attendance of more than 5,000. Our befrienders also provided direct support to bereaved parents and family members outside meetings. At least another 1,500 accessed such support, and many others received support indirectly, through social media interactions.

When we asked our befrienders what they feel the impact of their support is, they emphasised how they are creating a community that understands the experience parents are going through, minimising the sense of loneliness. They are also creating a safe space for people to express their feelings without feeling judged or upsetting others.

This is a crucial part of Sands' model of bereavement support, to reduce isolation, normalise the feelings of grief parents are experiencing and give opportunities to grow through their grief and create a positive legacy for their baby. Parents and families volunteer in fundraising, befriending, raising awareness through social media and linking with their local hospitals to share Sands' work and resources.

Sands volunteers established nine new memorial spaces, where families can come to reflect all year round. At these, and in other spaces around the UK, our groups ran memorial events on special occasions, such as Mother's Day, Father's Day, Wave of Light, and Lights of Love, and on other days throughout the year. Inspired by the Sands United teams, many of our befrienders also experimented with offering regular support in new ways, such as walking in the park, art activities, and singing.







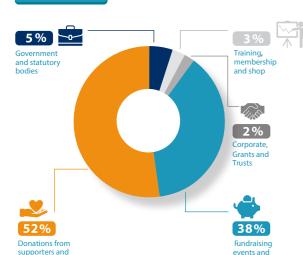
To grow as one strong, sustainable and effective organisation

Our Finances

Total income

 \blacksquare

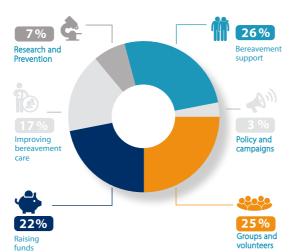
£3,713,207



For every £1 we spent on generating funds we raised an average of £4.19









Maintaining and growing our income

During 2019/20 we undertook a restructure of the fundraising department, which was completed in March 2020, positioning Sands to build on core strengths and seize new opportunities. In addition, we focused on a number of strategic activities to further diversify Sands income and better weather economic headwinds:

- Developed Sands' Case for Support to underpin all fundraising and engagement activities.
- Developed digital fundraising and online affinity marketing to establish new major funding stream including Facebook fundraising, Sands Weather Lottery, Amazon Smile and Give As You Live.
- Grew Corporate Partnership portfolio and won major new partnerships including Marks and Spencer (Sparks Loyalty Card scheme) and NatWest Group.
- Led a coalition of nine other baby and child loss charities to collaboratively develop a new major annual fundraising event Big Steps for Small Feet: Ben Nevis Night Climb.
- Established Sands United relationships team, strategy and brand to build on success and reach more people, raise vital funds and awareness to grow the model across the UK.
- Established dedicated BLAW online shop and re-launched a new improved Sands online shop.



Responding to the challenges of Covid-19

In March 2020 as the Covid-19 pandemic grew we rapidly overhauled communications and engagement activity to ensure Sands responded quickly to an evolving external narrative with a completely new message framework and updated case for support.

- Rapidly launched the Sands Resilience Appeal in March 2020 to mitigate immediate impact of cancellation of mass participation and community fundraising.
- Newly created Trust & Statutory Fundraising team responded quickly to available funding opportunties and submitted £2m in applications and received more than £700k between March and October 2020.
- Rapidly developed a new portfolio of fundraising and digital products to respond to social distancing measures and enable supporters to continue to support.
- Launched new digital portal service for Groups network, enabling Groups to fundraise more easily for local and national projects and provide a seamless UX for supporters at a regional/ community level.





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

Public Affairs and Campaigns

Social Media followers 16,549

513,504 Website users. This is up by previous year

Sands Awareness Month

The overall aim for Sands Awareness Month 2019 was to make sure men of all ages who have been affected by baby loss felt more confident in seeking support in a way that is right for them. The campaign was launched with coverage on Sky News and Mail Online and the support of our Ambassador Matt Allwright. A dedicated micro-site aimed at men,

featuring support, advice and inspirational examples of men finding their way through grief was accessed by nearly 2000 unique users during the month. The fundraising activity during June raised more than £20k for Sands.

Breaking the silence around baby loss

In November 2019 we welcomed Malin Andersson as our new Ambassador. Malin was supported by Sands when her baby daughter Consy was born on 23rd December 2018. Consy was born seven weeks early in December and was cared for by Great Ormond Street Hospital, but sadly died on 22 January.

In March 2020 Katie Ingram shared her story of experiencing her first Mothers Day after a stillbirth and being a mum to her beautiful daughter Ottilie Eve for The Independent "I am a mother – but not the mother I thought I would be." bit.ly/Independent_KatieIngram

On World Childrens Day 2019 Chris Evans and The Chris Evans Breakfast Show donated £5000 from the funds raised through CarFest 2019.

Bereaved mother, Sam Kitson, produced a children's picture book called 'In The Stars' in memory of her daughter Kitty, to help children understand about the death of a baby.

Baby Loss Awareness Week (BLAW)

A brand new website was launched with improved content, story-telling and user experience.

A digital mosaic brought together over 6,000 images that people posted on their own social media channels into one interactive space.

More buildings and landmarks than ever (267+) lit up across the UK including London's Marble Arch, BT Tower, Millenium Bridge Gateshead and the Kelpies event which was live streamed on BLAW Facebook

The Week was featured in more than 300 pieces of national/regional media coverage.

The #WaveofLight was the top trending hashtag on Twitter on 15th October, and we shared live feeds on both the Sands and Baby Loss Awareness Week Instagram and Facebook channels



820,922 people reached on Facebook **189,712** viewers

34,500+ engagements



9000+ viewers on instagram, hundreds of tagged images, videos and stories

Lessons Learned

It is impossible to consider the lessons learned during 2019/2020 without acknowledging the impact of Covid-19 on the last few weeks of this period, and then during the following months. Amongst other things we have changed the way we interact with others, the way we learn, and the way we work. There was significant learning during 2019/2020 which included:



Research and Prevention

Maintaining a focus on safety initiatives to reduce perinatal mortality is key, as these have proved to be fragile under pressure; this focus needs to be supported by clear messaging that the current rates of baby death are not inevitable.

Establishing an effective and swift feedback loop from Sands support services, which allows emerging issues to be fed back to key decision makers, can be a crucial element in improving safety for pregnant women and their babies.



Improving Bereavement Care

Investing time in setting up systems and digital platforms that connect healthcare professionals allows us to support them better. We can enable learning to be shared, new

resources to be created, and problems and solutions to be addressed. It is important that the NHS understands and believes that we are here for them.



Bereavement Support Services

We can reach a wider and more diverse audience guickly and flexibly by embracing digital, online and virtual support services. New services set up at pace to respond to need and improved with real-time feedback, can be a

very effective way to innovate and adapt. Diversifying our materials through use of different languages and images is one way to demonstrate that Sands is here for anyone affected by the death of a baby.



Income and Engagement

As the Covid-19 pandemic continues we are working together across the organisation to seize on all funding opportunities as soon as they present themselves. It is vital that we remain relevant in our organisational communications narrative and connect our supporters with the impact they are making. We are also taking a digital-first approach and continue to pivot our product portfolio to adapt to social distancing measures with a clear focus on being both relevant now, and in the longer

term, as we emerge from the crisis. A key part of this approach involves balancing product led and cause led approach with a broad portfolio of activities; for example, the Resilience appeal, challenge products, family fun products. We must also balance our resources to address the need to build volume to mitigate anticipated drops in average gifts and pursue large major funding opportunities (e.g. appeals, multi-year funding opportunities institutional/ major donors)

With gratitude to the individuals and organisations that support us and make our work possible.

Hall Hunter Foundation James Inglis Testamentary Trust Macfarlane Charitable Trust Mazars Charitable Trust Mrs M A Black Charitable Trust **OBE** Foundation Hickinbotham Charitable Trust St John's Church Grants Committee The Clephane Hume Charitable Club Towers Trust The Leonard Laity Stoate Charitable Trust The Sir James Reckitt Charity The Worshipful Company of Horners TJX UK Foundation Acuity Law Barrie Beard Charles Stanley Solace Jewellery First2Protect Aldermore Allen & Overy Northern Ireland Amazon Community Foundation Glory Global Amazon UK Ltd **AO Smile Foundation** ASDA Foundation Avison Young Community Fund Aviva PI C BabyPrem Ltd Bambinos and Beyond Barclays Banking Group

BP Foundation BP Shipping **Brand Events** Brit Insurance Michael Barnard Charitable Trust British Telecommunications PLC JN Bentley Ltd Michael Barnard Charitable Trust Bulletproof Agency Network Ltd Johnsons Workwear Buzzworks Holdings Cactus Consultants Chittendens Funeral Services Christies Care Ltd. CIPFA. Chartered Institute of The Adrian Swire Charitable Trust Public Finance and Accountancy and Wales Coca-Cola European Partners Colwyn Bay Crematorium Costco Southampton Creative ITC Day Lewis Pharmacy Delphi Technologies DontSendMeACard.com Ltd Easyfundraising.Org.Uk Ecclesiastical Insurance Ellesmere Port Soroptimists Enterprise Holdings Foundation Co. Ltd. Enterprise Rent-A-Car Ernst & Young LLP Fold a Box Glory UK Golden Acre Dairy Foods Ltd H & F Legal HBP Group Healthcare Conferences UK Hiscox Insurance Hitachi Capital Consumer Finance Recycle4Charity.co.uk Holland and Barrett **HRG Spectrum Point** HSBC Bank

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RitMir Ventures Ltd Scania Financial Services Seament SEIB Insurance Brokers Simpson Millar **Smart Qualifications** SMR Automotive Mirrors UK Ltd. Southampton City Council Start Financial Services Step Change Debt Charity Storal Learning Sword Tarmac The Entertainer The Fertility Partnership The Giving Machine The JC & KC Foundation The Kiltwalk The Sheriffs Office The Vodafone Foundation Together O'Neills Irish International Sports Top Cashback (UKC Systems Ltd) Toyota Manufacturing (UK) Ltd Treswithian Downs Crematorium UDG Healthcare plc Underdog Coffee Unipart Rail Unison Lanarkshire Health Branch Vernacare Charity Society Waitrose & Partners Wessex Fertility Westex Carpets William Grant Foundation Work For Good Ltd Wright, Johnston & Mackenzie LLP



Bellway Homes

Bordon Hill Nurseries Ltd





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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

