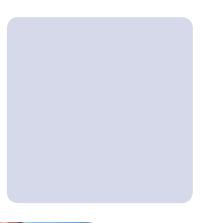




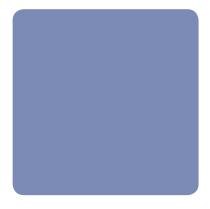


HOW SANDS IS MAKING A DIFFERENCE











IMPACT REPORT 2015/16







15 BABIES ARE DYING EVERY DAY IN THE UK 15 BABIES TOO MANY

OUR MISSION

Sands is the stillbirth and neonatal death charity. We support anyone affected by the death of a baby, work to improve bereavement care and promote research to reduce the loss of babies' lives.

Our vision

Our vision is for a world where fewer babies die and when a baby does die anyone affected by the death receives the best care and support for as long as they need.

Our purpose

We have three core aims that drive and underpin our work:

- 1. We support anyone affected by the death of a baby.
- 2. We work in partnership with health professionals to ensure that bereaved parents and families receive the best possible care.
- **3.** We promote improvements in practice and fund research that could help to reduce the loss of babies' lives.

Our values

We are compassionate, dedicated and strive for excellence in everything we do. Our aim is to provide inclusive and informed support; our response is individual and sensitive. Our working relationships are collaborative, based on trust, integrity and respect. We are passionate about sharing and improving knowledge. In 2014 we launched our 3 year strategy to help us take our vision and purpose forward and we identified five key priority areas to define our work:

- Better support
- Improving bereavement care
- ▶ Effective organisation & increased revenue
- ▶ Fewer baby deaths
- Bigger, better profile

2015/16 marks the middle year of the strategy. It was a transformational year, with new leadership, an expanded staff team, and many new projects taking shape. Through people's personal stories, this Impact Report aims to shine a light on our work in all five areas.

As a charity we are continuing to grow and as we do so, we hope we can demonstrate progress in achieving our goals: ultimately a world where fewer babies die and where bereaved parents receive the highest possible standard of care and support.

Thank you very much for reading and for your support as we continue our journey.

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WELCOME FROM OUR NEW CHIEF EXECUTIVE

I am delighted to introduce the 2015/16 Sands Impact Report. I joined Sands in August 2016, and feel very privileged to have joined such a fantastic organisation.

Being able to share Sands' achievements over the past year underlines the real difference that Sands makes to so many people who have been devastated by the death of a baby.

In many ways stillbirth and neonatal death have been hidden from public view. The devastation and impact of bereavement is known to all those affected, but not necessarily acknowledged and understood more widely.

Sands has led the way in highlighting how important this issue is, and in November 2015 the Secretary of State for Health, Jeremy Hunt, announced a government ambition to halve the number of stillbirths and neonatal deaths, brain injuries and maternal deaths by 2030 – and reduce them by 20% by 2020. This commitment has put stillbirth and neonatal death firmly on the national policy agenda.

But Sands is unique in not only working to reduce the number of babies dying, but also in holding bereaved parents and families at the heart of our work. This means ensuring that the right support is there for parents and families when they need it, and that the bereavement care they receive is of an excellent standard.

Our improving bereavement care training has gone from strength to strength, reaching professionals from a variety of backgrounds not just midwives and we recently launched the 4th Edition of our indispensable publication *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals*. This essential benchmark for good practice will enable all health professionals to provide the best possible care.

There is no doubt that our 99 local groups remain our backbone. Their work throughout 2016 has enabled us to provide high quality, localised bereavement support to thousands of families, and also to maintain good links with maternity services across the country. In addition our support literature, helpline and online forum provide vital support nationally.

What has struck me is not only the passion and commitment of all those involved with Sands, but also the generosity of spirit. Thanks to the incredible efforts of our fundraisers we saw our income rise again, a staggering 18.5% increase on last year.

Our amazing supporters run marathons, jump out of planes, cycle hundreds of miles and take part in thousands of other activities to help us keep doing what we do. To our fundraisers and to our many hundreds of volunteers, an enormous thank you.

Sands has made a real difference for bereaved parents and families over the last year, and working together we can make even more of a difference going forward. I feel truly lucky to be part of this amazing organisation.

Dr Clea Harmer

RAMMEN

4

2015/16: OUR HIGHLIGHTS



We responded to

6,154

helpline calls and emails



124,000

Bereavement support booklets distributed



Our campaigning was rewarded: the government announced an ambition to cut stillbirths and neonatal deaths in England by 20% by 2020 and 50% by 2030





Our Wave of Light campaign during Baby Loss Awareness Week trended on Twitter and reached over

10million

Facebook users



We provided support via our network of

99

Sands Groups



Sands Groups funded 18 new or improved bereavement care suites and 9 new or improved memorial gardens



We financially supported 6 research projects with funding of

£167,869



670



pieces of print and radio coverage were generated with a reach of over **64million** people



290,330
Website visits, 69% of which were new



2,300

healthcare professionals improved their bereavement care skills with our training



With our support a 15% reduction in the number of babies dying in Scotland in 2015 was achieved



raised from running and challenge events including nearly £70K from the London Marathon alone

5

SUPPORT AND UNDERSTANDING

Providing support is at the heart of what we do. From those first moments when a family learns that their baby has died, or is likely to die, to any number of years later, we provide warm empathetic support and practical information to anyone affected by the death of a baby.

Regaina Cawley turned to Sands in December 2015 after her son Elijah was born prematurely while she and her partner were on holiday in the Caribbean. He lived for just 10 minutes. Their distress was compounded by being far from home but thanks to our online resources they were able to access information they needed. Regaina has continued to access support from Sands for support since she returned home. This is Regaina's story:

We were visiting St Vincent to see my partner Ozan's family. Two days into the trip I knew something was not right. I tried not to panic but that evening the cramps became so bad that we rushed to hospital.

I gave birth to Elijah early in the morning. He was so cute. They put him on my tummy. He was so incredibly warm, so small. I stroked his head and told him 'I love you my little boy'. He was gasping for breath so they took him away. Then the doctor came back to say he had died because he was severely premature. They just left me there and I cried and cried.

Afterwards was torture. I was moved to the maternity ward opposite a woman and her new baby. Staff were reluctant for me to see Elijah. I found he had just been left on a counter. It was the first time I got to see him properly.

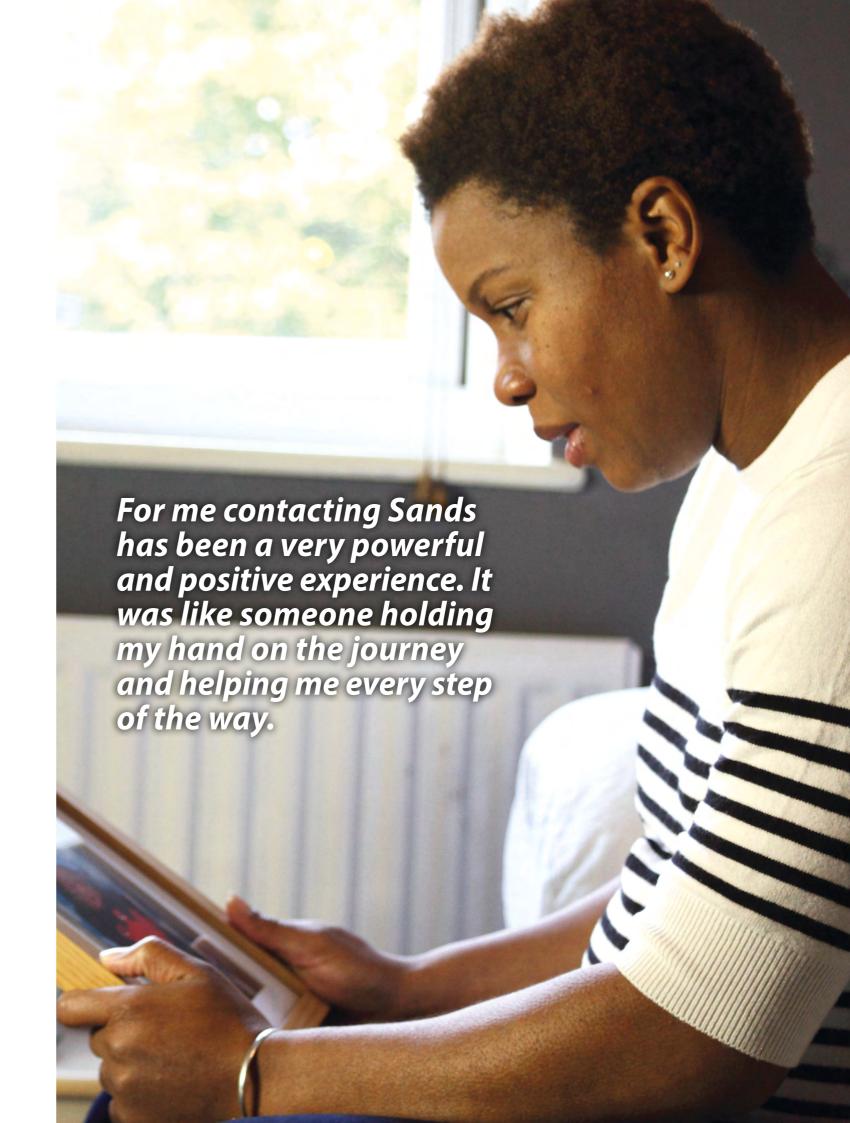
We stayed in St Vincent but I spoke to my UK doctor who thankfully told me about Sands. I used the Sands Forum and website relentlessly every day for a month after Elijah died.

Feeling abandoned so far away from home, the Sands Forum allowed me to share my story and connect with others. The website provided the stepping stones I needed to get through. I found out the value of making memories through things like taking Elijah's footprints and handprints. I found out how to plan a funeral. I shared links relating to dads with Ozan so Sands helped him too.

We decided to bury Elijah there. We picked a beautiful burial site under a tree. We went shopping for baby clothes for the funeral. I watched as they dressed him. It was upsetting but I'm glad I did it. We took him to the cemetery in his tiny coffin and I put him in the grave myself. I felt immense pride that we had created him.

As soon as I got back to the UK I found out about Swindon Sands and was able to meet people who have had the same experience. Meeting everyone has given me strength.

For me contacting Sands has been a very powerful and positive experience. It was like someone holding my hand on the journey and helping me every step of the way. Sands was there for me from the start and I will never forget that.





SANDS GROUPS: DRIVING CHANGE

Our nationwide network of Sands Groups are an integral part of our support programme, they also play an important role in improving bereavement care. Run by bereaved parents, Sands Groups provide unique support and strive to improve the experience of others.

In the past year Sands Groups have held hundreds of support meetings, funded 18 new or improved bereavement care suites and nine new or improved memorial gardens. They have arranged bereavement care training at their local hospitals, sponsored midwives to attend our Sands, Bliss and the Royal College of Midwives annual conference as well as numerous other projects.

Emma Kedge from Surrey Sands is a classic example of one of our group volunteers and last year she played an important role in the creation of a new bereavement care suite. This is Emma's story.

The noise that came out of me when I was told my baby had died still haunts me today. At that time there wasn't a bereavement suite at Kingston Hospital, and I was distraught when I learnt I had to give birth to Oscar on the labour ward. The care I received however was amazing and everything was tailored to our needs. Part of that care was being given a Surrey Sands memory bag. It contained Sands booklets and other truly thoughtful items.

I found it so comforting to know that other people had been through the same thing and cared so deeply. A month on, my husband and I attended a Surrey Sands support group. I didn't feel the need to talk, it was enough to know that everyone there just 'got it'.

Today I am on the Surrey Sands committee and act as Kingston Hospital Liaison. Our group works with seven hospitals and until recently Kingston was the only remaining one without a bereavement suite. When space became available last year, we were thrilled. The challenge was to turn two small offices into a positive environment in which families can spend time with their babies. Representing Sands, I, alongside others, provided input on the architect designs and Surrey Sands fully furnished the room.

Last November The Daisy Room officially opened. It is named in memory of Daisy Wilson whose parents provided major funding for the room alongside donations from the Hospital's charity 'Born Too Soon', Surrey Sands and the Department of Health. Sadly, even before the suite had been officially opened, it had already been used several times and since there have been occasions when two families have needed it at once. It's hard to accept that in this day and age one bereavement suite isn't enough.

I continue to work closely with the hospital. In February I gave a talk to raise awareness of Sands and arranged for a bereaved mother to speak. We had such positive feedback that we have been asked to repeat it with a father speaking. For me this is what being part of Surrey Sands is all about: working together to continue to improve the experience of future parents at their time of need.

WORKING HAND IN HAND WITH HEALTHCARE PROFESSIONALS

The quality of bereavement care that families receive has a major impact on their ability to cope in the future. Sands has taken huge strides in this area. Last year alone we improved the bereavement care skills of over 2,300 professionals through our bereavement care training and e-learning platform.

Bereavement specialist midwife, Jane Laking, at the Whittington Hospital in London, was a trailblazer when she first took on the role 13 years ago. She has worked closely with Sands ever since, welcoming bereavement care training initiatives and supporting Sands' calls for improvements in maternity care across the UK to help save babies' lives. This is Jane's story.

Being a midwife is a vocational career. I studied midwifery at Leeds and moved to the Whittington in 2001, where I was a community midwife. When the new bereavement specialist role came up, it was a bereaved mother herself, who told me I should go for the job. So many people feel uncomfortable talking about bereavement. You cannot make it better, but you can make it a little better.

Sands has been there from the start. It is an amazing charity and it does a hugely valuable job. We always recommend Sands to be eaved families.

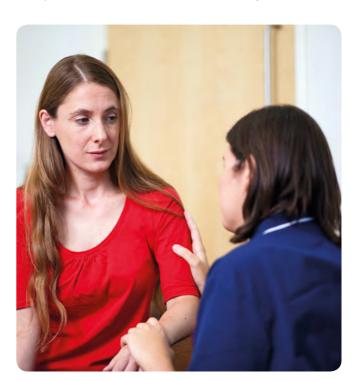
For professionals, the Sands Guidelines are fantastic and powerfully written. It is a vital resource. The Sands audit tool for maternity services has also had a big impact. People in the NHS have taken a lot of notice of it in the last year.

Families always give good feedback about the Sands groups. The ripple effect of baby death on families is often underestimated, but not by Sands. Parents, grandparents, siblings, aunts, uncles, close friends – they are all affected.

Because of Sands' efforts the resources available in hospitals are getting better and better. Ordering leaflets and family support packs from Sands helps us know families are getting the information they need. We also have strong links with the North East London Sands Group.

About 80% of my job is bereavement support. We sadly have about 14 to 18 stillbirths a year and my casework list totals 60-80 families at any one time. But 20% of my time is spent in practice development, teaching midwifery and on clinical shifts to keep my skills up. I really value the professional bereavement training that is now offered to health professionals by Sands, too.

Reducing the number of our babies dying every day in the UK is possible. I know that Sands is doing everything it can to improve both bereavement and maternity care.







PREVENTING BABY DEATHS

Sands is making a significant difference through work to reduce the numbers of babies dying across the UK.

► Tackling one of the highest perinatal mortality rates in Europe

Sands has been calling for a national focus to reduce perinatal deaths since its Saving Babies Lives report in 2009.

Scotland and Wales were the first to hear us and we continue to work closely with their government-led national stillbirth reduction programmes, running since 2010 and 2011 respectively. In 2015

Scotland achieved its 2011 target to reduce stillbirths by 15%. In November 2015 England caught up with Jeremy Hunt, Secretary of State for Health's announcement of an ambition to reduce stillbirths and neonatal deaths by 20% by 2020 and by 50% by 2030.

Collaborating on public reports and NHS initiatives to reduce deaths

Collecting better national information about baby deaths.

Sands is a vital member of the MBBRACE-UK (Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries across the UK) collaboration, putting the voice of families at the heart of the national programme to understand where and why babies die in the UK. Sands, together with Professor Gordon Smith, asked that MBRRACE-UK's first confidential enquiry look at the causes of death for babies who die at the end of a full-term pregnancy. Professor Jennifer Kurinczuk (pictured), the National Programme Lead for MBBRACE-UK:

In November 2015, our confidential enquiry into antepartum stillbirths at term concluded that 60% of antepartum stillbirths might have been prevented with improvements in the quality of care – this significant finding

will influence how maternity services are developed going forward, and will save babies' lives.

Better Births and the maternity services of the future

Sands was invited to join the National Maternity Review Panel in England and we ensured the voices of bereaved parents were heard. Safety is central to the final report, Better Births, which sets out a vision to transform care in maternity services over the next 5 years: as a member of the Stakeholder Council, Sands will advise the Maternity Transformation Programme in realising this vision.

Saving Babies' Lives Care Bundle

Sands helped develop NHS England's Saving Babies' Lives Care Bundle, aimed at reducing stillbirths through improvements to care. It launched this year and has been adopted by trusts across the country.

Lancet Stillbirth Series 2016

Sands supported and funded two papers in this hugely influential academic series, which measured the UK's progress on reducing stillbirth rates compared with other high-income countries and highlighted what more must be done to prevent avoidable deaths.

Sands' Research Fund

Sands had its first open call for research funding applications in 2016, with an initial funding allocation of £300,000. Researchers across the UK proposed a wide range of projects and, at the time of writing, these are out for external expert review. Our processes will ensure that Sands funds the research mostly likely to make a difference.

FUNDRAISERS GOING TO EXTRAORDINARY LENGTHS

We rely heavily on the generosity of our supporters, the majority of which are bereaved families and friends. They tell us they fundraise for many different reasons; to say thank you to Sands for the support they receive; to do something positive in memory of their baby or babies; because they don't want others to suffer in the way that they have.

What fundraisers often don't anticipate is the comfort and moments of joy they can experience along their fundraising journey. Mary Stanley-Duke is one such fundraiser. Last year, she and her friends swam the English Channel in memory of her daughter Martha. This is Mary's story.

When my first daughter, Martha, was stillborn I had never heard of a baby dying before it was born. Sands was critical to my survival and subsequent flourishing from such a life changing event.

When admitted to hospital for the traumatic experience of giving birth to a dead baby I was given a pile of reading from Sands. It answered a lot of questions I didn't know I had. I considered things such as pictures, handprints and using the name we had decided for her (I had thought to not use it, I am glad I did). The midwife had training from Sands and was amazing, she had clearly been taught well.

Once home, with no one to talk to I used the Sands helpline; talking to someone who was 4 years on, who had gone on to have another baby, gave me hope. The Sands befriender training is a critical form of support for those just experiencing a loss.

Then I got pregnant and found myself in a lonely world. Not happily pregnant, but scared pregnant. Sands arranged for me to meet others who had lost a baby and who were pregnant again. We met most weeks, emailing in between.

These friends were my lifeline, where all the scary thoughts could be shared without judgement. Happily, we all had healthy babies and continued to grow our families. As time moved on the need to mark my first baby grew. Raising awareness was important to me and so fundraising for Sands became an aim, to give something back to the charity. I also wanted to give hope to those experiencing baby loss now.

Surprisingly, the training required for the Channel swim became therapy. I relived the horrors and realised that I was OK, that I could remember Martha without falling to pieces. Martha came, she changed my life. I experienced the darkest depths of human feelings but with support I came through. Now there is a sense of calm. And raising over £16,000 for Sands by doing a relay of the English Channel with some of my dearest friends was a bonus!



Thank you to Mary and all our amazing fundraisers, your efforts big or small make our work possible.





BERRY BROS. & RUDD: A BUSINESS WITH A BIG HEART

In 2015/2016, our corporate income increased significantly to £231K. This was due to a renewed strategic focus and significant fundraising events.

It is important that our corporate fundraising efforts continue to grow and not only help us to raise vital funds to support the important work that we do, but also help us to create a wider awareness of Sands' services within corporate HR departments.

One major success story we've had was being named official charity partner of Berry Bros. & Rudd. Nominated by employee Lisa Loveless whose son Max was stillborn in 2013, last year Sands gratefully received over £100,000 from their outstanding fundraising initiatives. Lisa herself has been brought great comfort from the recognition her colleagues and company gave her and her son. This is Lisa's story.

Losing Max broke me. He was our first baby, a beautiful boy. I had naively gone into the pregnancy thinking stillbirth was an old-fashioned thing so when I discovered that Max had died it was even more of a shock. It was torture. I was numb. My husband was distraught.

Afterwards you are left with psychological scars that you don't know how to fix but I know everything would have been a lot harder without the help of Sands. At the hospital we spent time in the bereavement suite created by Sands. It was more homely in there and gave us precious time to ourselves.

We were given a Sands memory box in which we keep Max's footprints and handprints, photographs and his little hospital wristband. We have been lucky enough to go on and have our daughter Rosie and we share these things with her. It's important to us that we keep Max in our lives.

It's very isolating when you lose a baby and although my friends and family were amazing, it was difficult for them to comfort me. The Sands Forum was my lifeline. I could speak to others who had gone through the same experience. I could be myself, I could laugh when I wanted, I could cry...

I feel very strongly about Sands and that is why I wanted to support the charity. After Max's funeral my husband and I raised £1,000 for the charity.

When my company, Berry Bros. & Rudd, made Sands their official corporate charity it meant so much to me. The whole workforce got behind it and for that I am forever grateful. Last year a dinner auction raised over £100,000 and there are more fundraising activities planned. Throughout the fundraising team at Sands has been really helpful, encouraging us along the way.

It is always moving when people are willing to give their all to support you. It helped me to know that Max did not die in vain, that something positive has come out of it. It has been an amazing journey.



RAISING AWARENESS

Raising awareness is essential if we are to make significant in roads in saving babies' lives so when Eastenders' actress Rakhee Thakrar agreed to become an Ambassador for Sands we were thrilled. Rakhee supported our 2015 'Star on our tree' Christmas appeal and other initiatives. This is Rakhee's story:

On 31st August 2015, an episode of Eastenders had the nation in tears as Shabnam and Kush's dead son Zaair, was born. I played Shabnam Masood and for me to tell this story as truthfully as possible, I set out to find out everything I could about the subject of stillbirth. It started with the normal internet searches, YouTube videos, books, etc. But the crucial turning point came on 12th May 2015 when I walked into the Sands office and met Bereavement Support Services Manager, Erica Stewart.

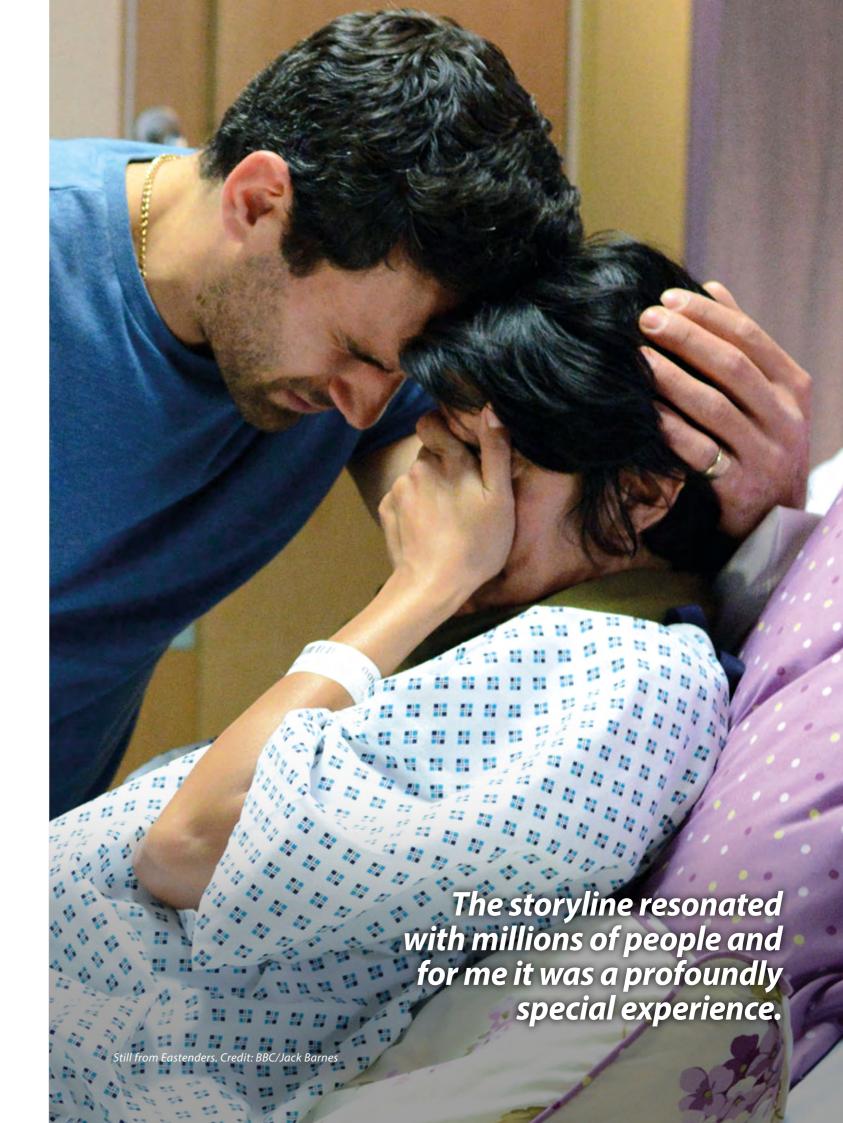
I spent almost 5 hours there that day and I heard stories, poems, facts, research studies, physical details/technicalities about stillbirth and most importantly Erica was able to help me to understand the type of grief that accompanies the death of a baby. I tried to remain as open as possible, asking questions but many a time I was stunned for words. I walked out of that office into busy Oxford Street feeling quite numb, I knew we had a great responsibility to do all we can to tell this story truthfully and sensitively. I was determined to do so. In the following days and weeks I met with several bereaved mothers who shared their experiences generously and with absolute openness.

I felt honoured to have been let into this world that, because of the taboo that surrounds baby death, is often not seen. There were details from these brilliant women that made their way into Shabnam's story. I could not have played her the way I did without these extraordinary mums. I spoke with a midwife to understand the technicalities of giving birth to a dead baby, the kind of care provided, pain relief etc.

She also kindly joined us on set so she could guide me on specifics like contractions and labour. There are no words to explain how important Sands' involvement was for all of us, from cast to writers to producers. For me in particular, Sands provided me with endless resources, blogs, poems, leaflets, pictures... helping me to build this world that I had never known about. The charity committed many hours in phone calls and emails answering my many questions. We couldn't have done this without Sands' support.

The research lasted right up until December 2015 when I left the show, as you may know, the grief following the death of a baby is extremely complicated so it was vital we didn't stop. The storyline resonated with millions of people and for me it was a profoundly special experience. It was impossible to walk away, so when Sands asked me to be an ambassador I was honoured and immediately said YES.

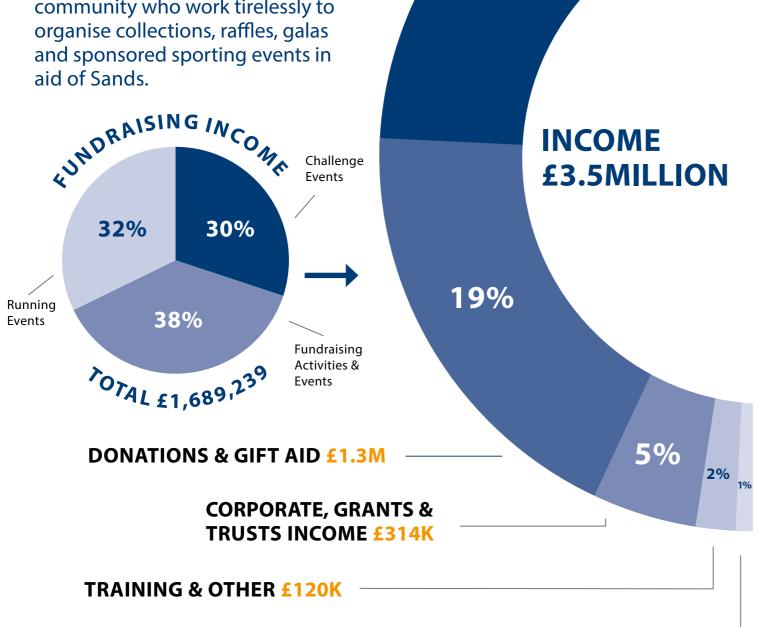






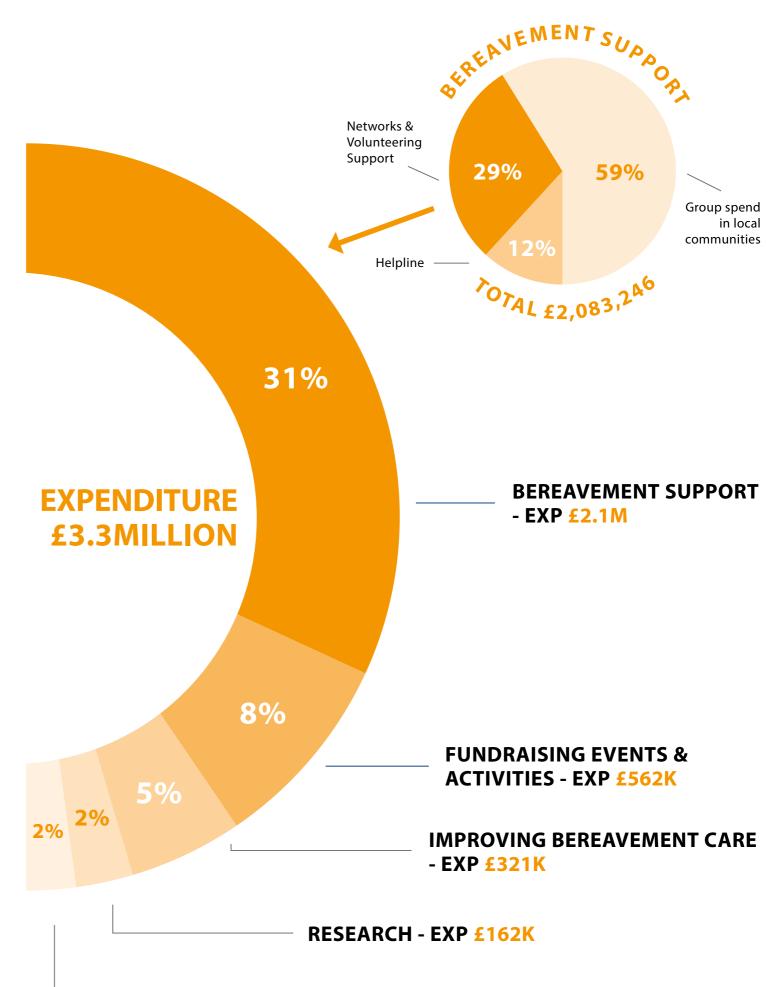
driven by record levels of income across a number of our fundraising streams including generous one-off gifts from individuals and continued support from those regular donors.

We also continued to receive significant contributions from our incredible supporters in the community who work tirelessly to aid of Sands.



25%

STATUTORY INCOME £51K



RESEARCH GRANTS - EXP £140K



LOOKING FORWARD: CHAIR'S REPORT

This is an exciting moment for Sands. 2016/17 marks the final year of our current three-year strategic plan, which means we are beginning to think about the next three years: where we want to be and what we want to do, by 2020.

This is our chance to make a real difference for bereaved parents, their families, friends, and the professionals that care for them. It's also our chance to significantly impact on the rates of stillbirth and neonatal death, as we throw our efforts even more strongly behind research and prevention to reduce the number of babies dying in the UK.

We will be conducting a full review of our current work. This will involve the whole organisation: volunteers, members, parents, staff, trustees, all working together as one, to understand what we do well and how we can do things better. We will ensure that we continue to provide an exemplary support service for bereaved families, both nationally and locally.

We want to grow and expand our services for professionals, providing high quality training and teaching resources, and other professional tools to enable those caring for bereaved parents to do so to the highest standard.

Promoting and funding research remains a key priority, as we work towards a world where fewer babies die. As part of this aim, we intend to further our work with all four UK governments, ensuring that reducing the rate of stillbirth and neonatal death is kept high on the national policy agenda. We will continue to work to raise our profile, ensuring that Sands and the issue of baby loss are never far from the public consciousness.

And we will continue to work in partnership with charities across the sector and beyond, to maximise the impact we can have.

This report demonstrates some of the incredible impact Sands has had on people's lives across the UK. We're looking forward to building on this over the next three years and beyond. On behalf of the Board of Trustees, I'd like to thank everyone who has been part of the journey so far and welcome those joining us as we head into the future.

A Mc Cafferty

Angela McCafferty

OUR TRUSTEES

Angela McCafferty (Chair)

Derek Jenkins (Vice Chair)

Michael Smith (Treasurer)

Reg Bailey CBE

Sarah-Jane Evans

Edward Ford

Stephanie Frearson

Alyson Hunter

Joel Mitchell

Zoe Renton

Catherine Roberts

THANK YOU

And finally a huge thank you to all our volunteers, fundraisers, research participants and professional partners without whom we would not exist.

Thanks to the following corporate partners, trusts and foundations for your generous support:

- **▶** Artemis Charitable Foundation
- **▶** Aspect Capital
- **Begbies Traynor**
- ▶ Berry Bros. & Rudd
- **CAPCO**
- **▶** Confused.com
- **▶** Deans of Huntly Ltd
- Horizon Discovery
- **▶** Lakeside North Harbour
- Oakleaf Partnership
- **▶** Roche Products Limited
- ► Royal Air Force Shawbury
- Sharegift
- St James's Place Foundation
- ► Teddy's Wish
- **▶** The Sir James Reckitt Charity
- **▶** Trapeze Group
- **▶** Truemark Trust

TOGETHER WE WILL CONTINUE TO MAKE A DIFFERENCE AND SAVE BABIES' LIVES



If you would like any further information or support please contact us or visit our website.

Support: 020 7436 5881 helpline@uk-sands.org

Enquiries: 020 7436 7940 info@uk-sands.org

www.uk-sands.org

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