

# IMPACT REPORT 2016/17

Creating a future where fewer babies die

### **KEY HIGHLIGHTS**

316,935 website visits, **72**% of which were new

We responded to 5,246 helpline calls and emails

110,000 bereavement support booklets distributed

106 Sands Groups providing peer support throughout the UK

Sands Groups funded 9 new or improved bereavement care suites and 11 new or improved memorial gardens (over £240,000)

2,502 healthcare professionals improved their bereavement care skills with our training



1,048 pieces of print, TV and radio coverage were generated



We directly funded 4 new research studies, equating to £250,000



on 15 October 2016 as part of Baby Loss Awareness Week



£1,100,000 raised from running and challenge events

#### Foreword

A message from our Chair of Trustees A message from our Chief Executive

#### Better support

Helpline & online support forum Family support packs & memory boxes Local support

#### Research and prevention

Sands research fund Perinatal Mortality Review Tool Safer Pregnancy website National mortality reduction work Stillbirth and neonatal death rate Investigations into baby deaths Maternity Transformation Programme

#### Improving bereavement care

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# **OUR VISION**

We work to reduce the number of babies dying and to improve care and support for anyone affected by the death of a baby.



# **OUR MISSION**

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's needed.

# **OUR CORE AIMS**

- **1**. To support anyone affected by the death of a baby.
- **2**. To work to improve bereavement care.
- **3**. To promote research and prevention strategies to reduce the loss of babies' lives.

# **OUR VALUES**

- We will be compassionate, collaborative and evidence-based.
- We commit to working as one organisation; learning from experience and striving for continual improvement through innovation.
- We will be open and honest; working with respect and integrity, showing empathy, and being inclusive in everything we do.

#### STRATEGIC OBJECTIVE I

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

#### STRATEGIC OBJECTIVE II

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

#### STRATEGIC OBJECTIVE III

To grow as one strong, sustainable and effective organisation.

#### STRATEGIC OBJECTIVE IV

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

#### **Our Trustees**

Reg Bailey CBE (Chair) Angela McCafferty (Vice Chair) Michael Smith (Treasurer) Sarah-Jane Evans Edward Ford Stephanie Frearson Alyson Hunter Derek Jenkins Joel Mitchell Zoe Renton Catherine Roberts Susanna Speirs



**Reg Bailey CBE** Chair of Trustees, Sands

## A message from our Chair of Trustees

The launch of a new strategy is a significant moment for a charity – and so it is for Sands. The new strategy allows us to clearly set out what we want to achieve by 2020.

In the UK, the number of babies who die either before, during or shortly after birth is significantly higher than many countries in the developed world. And of course, behind these blunt statistics lie too many individual sad stories of loss. More needs to be done, and our objective to reduce these numbers reflects the challenges we know lie ahead.

Not only are we putting ourselves at the forefront of research into stillbirth and neonatal death through the launch of the Sands Research Fund, but we are also committed to undertaking audit reports into bereavement care across the UK so we can recommend measures to improve the care that families receive.

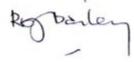
We believe that every parent deserves equal and excellent bereavement care, and to ensure this happens we are leading on the development of the National Bereavement Care Pathway. This will be

rolled out over the next few years, and is the result of a collaborative approach that has involved a wide range of stakeholders.

However these are not the only challenges we face: fundraising practice has come under scrutiny for all charities and voluntary organisations, and new data protection legislation will be introduced in 2018 which will reform how charities store information on individuals. It is an important step forward for the sector and here at Sands we are already working towards implementing the necessary changes.

It is crucial that we are unafraid to look at and evaluate whether or not what we are doing is really addressing our overall goals. So this report highlights some of the vital work Sands has undertaken to better understand why babies die and where improvements can be made. On behalf of the Board of Trustees, I would like to thank our passionate staff, volunteers and supporters for their commitment to Sands' cause. You are the reason for our progress to date and are pivotal to Sands' journey for the future.

Many thanks.



**Dr Clea Harmer** Chief Executive, Sands

# A message from our Chief Executive

This impact report comes at an important time for Sands: it allows us to celebrate the significant achievements of our 2014-2017 strategy whilst also looking ahead to our new strategy, which outlines what we want to achieve by 2020.

Since the start of the last strategy we have seen the number of babies who die before, during or shortly after birth fall to 15 babies a day in the UK. However, if the Secretary of State's ambition to reduce stillbirth and neonatal death by 20% by 2020 and 50% by 2030 is going to be met, we still have much work to do.

A key element in reducing the number of babies dying is understanding the reasons why these tragedies occur – and the launch of the Sands Research Fund will ensure we contribute to this body of knowledge. We have also continued to call for a proper review of every baby's death, which includes the vital involvement of parents. Of course turning research into practice is essential, and one way we have done this is to disseminate the safer pregnancy messages through a new website.

We have also managed to reach more parents with our bereavement support – building capacity on our helpline and ensuring free family support packs are available wherever they are needed. Focus on improving the bereavement care that parents receive has led to the publication of the 4th edition of *Guidelines for Professionals* and the development of new training in the form of midwifery teacher materials and a specific day for health visitors.

Collaboration is an important way to make a difference for bereaved parents and families, and Sands has worked with a range of other organisations to raise awareness through Baby Loss Awareness Week. We have also raised awareness through advising scriptwriters on sensitive portrayal of relevant storylines in *EastEnders* and *Coronation Street*.

Our mission is to reduce the number of babies dying and to improve care and support for anyone affected by the death of a baby – and with your help we are making a real difference for families affected by the death of a baby as well as reducing this tragedy for future families.

Thank you.



# BETTER SUPPORT BY PHONE, ONLINE, IN PRINT, AND IN PERSON

Thank you so much. You helped me find my words and let me be just me for the first time in a long time. No one else listens anymore.

Long ago bereaved mother

**Photo:** Derby Sands "Always Loved Never Forgotten" baby memorial garden

# The Helpline

# Calls to the Sands National Helpline number are now free

Cost will not be a barrier to anyone wishing to contact us: in March 2017, the Sands Helpline number changed to

#### 0808 164 3332

which is free to call from landlines and mobiles. Alongside this free number, we introduced a call-handling system that allows us to better manage response times, understand the demand for our service, and develop the service to meet the needs of bereaved families.

# Sands National Helpline expands its capacity

We have recruited 3 new Helpline workers to respond to calls and emails, increasing our capacity by around 45%, which means we are able to support even more bereaved parents and their families from across the UK. Many of our Helpline team members first became involved with Sands through their local Groups and all offer compassionate, non-judgmental and empathic support to those affected by the death of a baby.

# Online support forum

Many bereaved parents tell us that when a baby dies they feel very isolated, as they don't know anyone else who has had a similar experience. In response, we created the Sands online support forum, which provides a safe space for bereaved parents to connect with each other and share their feelings 24 hours a day. Last year 1,423 new users joined the forum, with a total of 8,000 posts being made.



from those affected

by the death of a baby



Our Helpline also provides help and advice electronically and has a dedicated email service where we responded to over

2,300 messages

In total, we answered

5,246 calls and emails

from those seeking support following the death of a baby

Family support packs and memory boxes

Memory boxes help parents to create memories and collect keepsakes. Depending on their baby's gestation or age, parents may want to collect such mementoes as photographs, imprints of their baby's hand and foot, a lock of hair, scan pictures, a name band, clothes or a shawl, and certificates. Many hospitals offer parents a Sands memory box for their keepsakes.

Last year we sent **1,355** boxes to bereaved parents free of charge.

Sands provides free, personal and relevant information for anyone affected by the death of a baby, in the form of booklets – both in hard copy and to download from our website.

We distributed
110,000 support
booklets last year. The
most popular booklet
requested was: Deciding
about a post mortem
examination:
information for
parents, which was
ordered 1,816 times
by individuals, hospitals
and our support groups.

### Local support

#### New support Groups

#### Social media

### Support for hospitals

# Support for bereaved parents and families

# Bereavement suites and memorial gardens

A total of 7 new Sands Groups have been established to support bereaved parents at:
North Down, Monmouthshire,
West Kent & Medway, Wakefield & District, East Lincolnshire,
Hastings & East Sussex, and
West Berkshire. A total of 106
Sands groups are spread across
10 networks, and over 1,500
group support meetings were held across the UK.

Many of our Sands Groups communicate with their members via social media and keep them up to date with their news and charity-wide information. Our volunteers currently manage 92 Facebook pages, and 44 Twitter accounts.

The support our Groups offer to hospitals is important in many different ways, from ensuring there are memory boxes for midwives to use with bereaved parents, to paying for healthcare professionals to receive Sands' training. Last year 230 maternity units across the UK were supported by a Sands Group or network.

Sands befrienders play a vital role in offering support to bereaved families throughout the UK. Many of us know first-hand how much comfort and support a befriender can give. The reassurance of talking to someone else who has been affected by the death of a baby and who is nearby to phone or to meet is invaluable, so we've trained 111 befrienders since April 2016.

Befriender training

In September 2016 we carried out a capture exercise to identify how many bereaved families our volunteers support. At least 500 parents were supported during the month; at least 250 received support from befrienders outside support meetings; and 3,000 were receiving support online via Facebook.

Sands Groups also take on largescale projects at local level to improve outcomes for bereaved families. Last year our Groups:

- Established 4 bereavement suites/rooms in hospitals and updated 5 existing bereavement suites/rooms
- Established 4 memorial gardens /rooms and updated 7 memorial gardens







My name is Des and my partner
Liz and I lost Ruby just six hours
after she was born at 23 weeks in
August 2010. I am so proud of how
she battled for life during that time,
and we briefly thought she might
survive. I grieve not only for her but
the potential of all she could have
been.

We were given Sands support literature containing useful information which came at the right time as it helped guide us to seek further advice. Family and friends offered support, and more came from people we barely knew. We also felt supported from the experience of other bereaved families.

I'm proud of the things that I've achieved in Ruby's memory, including raising several thousand pounds for charity and I now take more positive steps to help others when I can.

### **RESEARCH AND PREVENTION**

# Sands research fund: funding four projects

Understanding the causes of stillbirth and neonatal death is a vital part of Sands' work to reduce the baby death rate in the UK.

To this end we fund innovative and invaluable research into why babies die and how bereavement care for families can be improved. In 2016 we raised over £200,000 for our research fund, taking the total to £357,000 as at the end of the financial year. Eighteen applications were received in 2016 of which four were selected, having first been externally peer reviewed and rated by Sands' Perinatal Expert Panel, to receive awards in 2017-2018:

- Parents and Neonatal Decisions Study: Improving communication during conversations about limiting life-sustaining treatment in neonatal intensive care: Prof Neil Marlow (UCL Elizabeth Garrett Anderson Institute for Women's Health)
- Inequalities in stillbirth: a meta-narrative review: Dr Carol Kingdon (University of Central Lancashire)
- Prediction and prevention of perinatal death: Dr Asma Khalil (St. Georges Hospital, London)
- Outcome of resuscitated term babies with no heart rate detected at 10 minutes of age: Dr Gemma Sullivan (Edinburgh Infirmary)

# Development of Perinatal Mortality Review Tool

Around 60% of babies' deaths at the end of pregnancy might be avoided if care were different.

In Sands' 2012 Preventing Babies'
Deaths report we called for
maternity and neonatal units to
use a standardised review process
to understand events leading up to
the death of a baby. Evidence from
national enquiries tells us that
around 60% of babies' deaths
at the end of pregnancy might be
avoided if care were different, yet
the quality of local hospital reviews
of care is highly variable, with
many units failing to learn essential
lessons and repeating avoidable
mistakes.

We were thrilled that after five years of championing the need to establish good quality in-hospital reviews for when a baby dies, the government finally commissioned a group to push the work forward.

Sands and the Department of
Health led the expert group which
agreed what information should be
included in good-quality hospital
reviews. These recommendations
will form the basis for the new
web-based tool currently being
developed by a collaboration led
by MBRRACE-UK (Mothers and
Babies: Reducing Risk through
Audit and Confidential Enquiries
across the UK), which includes
representatives from Sands, the
PARENTS1 and 2 studies, the British
Association of Perinatal Medicine,

the Royal College of Obstetricians and Gynaecologists, and the Royal College of Midwives. The work is funded by the English, Welsh and Scottish governments.

Sands' aim is to ensure that parents' perspective of their care forms a key part of the review process, and that parents have honest and timely answers about the circumstances that may have contributed to their baby's death.

The new national standardised Perinatal Mortality Review Tool (PMRT) will be available by the end of 2017 and will be free to use for maternity and neonatal units.

### Safer Pregnancy website

We've been working to produce a Safer Pregnancy website for mums-to-be and anyone thinking of having a baby. The website was developed in 2016-2017, to go live in 2017.

We feel it's important that women and their partners know that sometimes things can go seriously wrong in any pregnancy and that they have access to reliable information about potential risk factors. How can women make well-informed decisions about their health and care if they don't know the risks? When we did research on this, women told us they wanted practical advice about how to reduce the chances of this happening as part of their pregnancy information.

We brought together the professional bodies for maternity, the Department of Health and partner charities in a stakeholder group to agree and endorse a set of key messages about stillbirth risks. Those messages form the basis for our Safer Pregnancy website. The site is designed to empower parents with the information they need to reduce the risks of baby death as much as possible. The information is straightforward and evidence-based; it links to professional guidance and to helpful resources for mums-to-be such as the Our Chance videos developed by Sands and the charity Best Beginnings.

Providing mums with the know-how and confidence to understand the various factors that can increase the risk of harm to them and their baby is one of many important ways we're working to reduce the baby death rate in the UK.









Organisations that helped develop content for the Safer Pregnancy website:

- APEC
- Bounty
- ICP Support
- Kicks Count
- MAMA Academy
- NCT
- Royal College of Midwives
- TAMBA

A site designed to empower parents to reduce the risks of baby death.

## National mortality reduction work in all four countries

# Reduction in stillbirth and neonatal death rate since Sands began its prevention work

# **Scotland:**

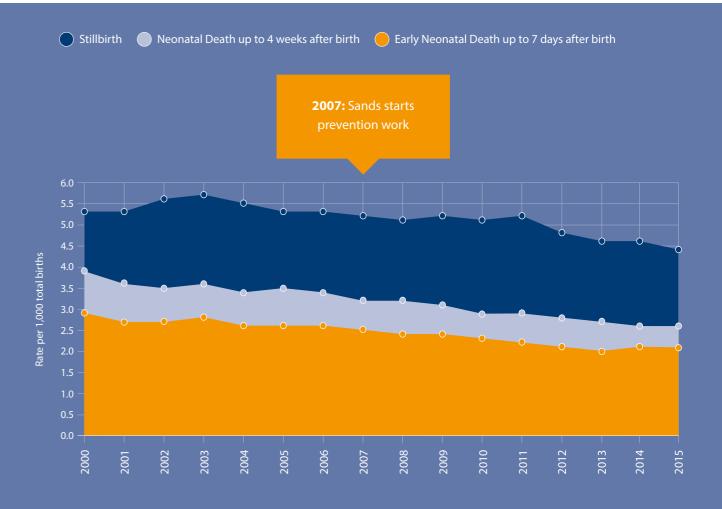
National Stillbirth Working Group

**Northern Ireland:** Northern Ireland Maternal and Infant Steering Group - NIMI

#### **England:**

Maternity Transformation Programme, Saving Babies' Lives Care Bundle

#### Wales: National Stillbirth Working Group



# Survey by Sands shows only a very small minority of parents were asked to participate in the review into their baby's death

In June 2016, the Royal College of Obstetricians and Gynaecologists *Each Baby Counts* report found that in a quarter of cases, the parents were not made aware that an investigation was taking place. 47% of parents were made aware that an investigation was taking place and were informed of its outcomes, but only 28% of parents were invited to contribute to the investigation.

A separate survey conducted by Sands of **287** bereaved parents revealed that only **32%** were told that the hospital was reviewing their baby's death. Of those who were told about a review, only 34% said they were invited to take part in it – **29** parents out of the **287** surveyed – and only around half of these report being satisfied with the process.

# Maternity Transformation Programme

In February 2016 the final NHS Maternity Review report *Better Births* was published. Sands supported the creation of this report by organising engagement days and running a survey specifically to gather feedback from bereaved parents about their care experiences.

As a result of this, NHS England made a commitment to delivering the recommendations in the *Better Births* report through the Maternity Transformation Programme. Dr Clea Harmer, Sands Chief Executive, is a member of the new Stakeholder Council.

Investigations into baby deaths are not of an acceptable standard [...] parents must be given the opportunity to input into the investigation into the death of their baby and the outcomes must be shared with them.

It's not about apportioning blame, rather ensuring everything possible is done to understand what happened so that we can learn from deaths and prevent future tragedies. ASMA'S STORY



Dr Asma Khalil, Consultant/Reader in Maternal Fetal Medicine and Obstetrics, St George's University of London, one of four researchers whose studies are being funded from Sands' Research Fund 2016/17

We were delighted to hear that Sands would fund our ambitious 15-month study *Prediction and prevention of perinatal death*.

We aim to find a way of identifying babies at high risk of death in the womb or shortly after

birth, so that they can be monitored more closely and delivered early if necessary.

This research will make a real difference to women whose babies are in trouble towards the end of pregnancy.

### **IMPROVING BEREAVEMENT CARE**

NHS England welcomes
this very comprehensive set of
guidelines and it is right for maternity
care providers to use it as a point of
reference in delivering compassionate
and effective bereavement care.

Matthew Jolly, National Clinical Director for The Maternity Review and Women's Health, NHS England

The fourth edition of the *Guidelines for Professionals* was made available in print and – for the first time – in digital formats. This was done to ensure the book was more accessible to health care professionals than ever before. As of March 2017 we had sold 650 copies of the *Guidelines*, providing professionals around the country with information on best practice bereavement care.

### Launch of Pregnancy loss and the death of a baby: Guidelines for professionals 4<sup>th</sup> Edition

We launched the fourth edition of our flagship publication for health and social care professionals, *Pregnancy loss and the death of a baby: Guidelines for Professionals,* in September 2016. The book provides a comprehensive update of the previous edition published in 2007 and fulfilled one of the objectives from our three-year strategy launched in 2014.

To produce this new edition of the *Guidelines*, we drew from research findings and on widespread discussions with health professionals, parents and voluntary organisations. 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.

We were delighted that upon publication, the new *Guidelines* were endorsed by over 20 organisations. More recently, the Scottish Government have also added their endorsement:













































## Workshop for health visitors developed

We expanded the range of bereavement care training we offer by developing and piloting training for health visitors, trained midwives and nurses, who work in the community to provide individualised care.

To develop the training we worked closely with the Institute of Health Visiting to create a oneday bereavement care workshop. This workshop provides health visitors with the knowledge, insight and skills to provide high quality, sensitive care to parents who experience the death of a baby, before, during or shortly after birth.

The workshop was piloted at two sessions in Edinburgh and Glasgow, and, following positive feedback from practitioners, was launched in Aberdeen in March 2017, already having provided bereavement care training to 47 health visitors.

This training is now a formal part of our training to improve bereavement care in the UK, and ongoing workshops are available to all health visitors

# National Bereavement Care Pathway developed to pilot stage

Since 2016 Sands have been leading on a crossorganisational project to produce a National Bereavement Care Pathway in order to ensure that all bereaved parents are offered equal, high quality, individualised, safe and sensitive care.

The research phase began in order to learn more about the many different pathways already being used by health professionals. We held learning events in Scotland and Wales and two parent stakeholder events in London and Manchester to ensure that parents are at the very core of the pathway. Finally, a project lead was recruited to complete the project, with the first wave to be piloted from October 2017 onwards.

#### **Charities:**

Sands; ARC (Antenatal Results & Choices); Bliss; Lullaby Trust; Miscarriage Association.

#### **Professional bodies:**

Institute of Health Visiting; NHS England; Neonatal Nurses Association; Royal College of Midwives; Royal College of Nurses; Royal College of Obstetricians & Gynaecologists.

#### Other partners:

A representative of the UK health research community.

## Bereavement care training target met and passed

From April 2016 to March 2017 we trained **2,502** health and social care professionals across the UK at **134** training sessions. This is an increase from 1,497 trained in the previous year.

Our bereavement care training programme is designed for anyone who deals with parents

who experience the death of a baby. This includes, but is not limited to, student midwives, midwives, obstetricians, neonatal staff, gynaecology staff, sonographers, GPs, health visitors, doulas and chaplains.

In our last strategy in 2014 we made a commitment to train

**3,000** midwives by 2017, and we're delighted that we've hit that target with time to spare. Our bereavement care training is vital in our aim to improve the care that parents receive when a baby dies, so this is a really important achievement for Sands and the parents and families we support.

2

98%

of participants felt their confidence in working with bereaved parents had improved since attending Sands' bereavement care training 99%

of participants would recommend Sands' bereavement care training to their colleagues 2.502

healthcare professionals trained (up from 1,497 2015/16)

Before attending I did not particularly feel that this was a subject of my role that particularly interested me but now I feel inspired to develop my practice and improve.

Healthcare professional

### Three new Bereavement Care Awards introduced



#### **RCM Awards**

At the 2017 Royal College of Midwives (RCM) Awards we presented the inaugural Sands Award for Bereavement Care to Clare Beesley, from Heart of England NHS Trust Bereavement Team.

The Award recognises excellence in bereavement care provision by maternity staff for women and their families when a baby dies. We see it as an impactful way to promote the high benchmark for what we believe bereavement care should be within the midwifery profession and beyond.

As well as the Sands Award for Bereavement Care being launched, the general award for 'Midwife of the Year' at the RCM Awards went to Laura Wyatt, a bereavement midwife who works closely with Cardiff Sands support group, for her work with parents who have experienced the death of a baby.

#### Scottish Bereavement **Care Awards**

The Scottish Bereavement Care Awards were devised by the Scottish Government Bereavement in Maternity Care national subgroup. The Awards are open to applications from health boards in Scotland and applicants are asked to identify local projects relating to bereavement care.

The purpose of the Awards is to provide health boards with incentive and assistance to develop their bereavement care, with the overall aim to improve the bereavement care provided to families who experience loss during pregnancy, birth or the postnatal period.

The award consists of a grant to contribute towards improving bereavement care and in 2017 Sands awarded three hospitals each with a £5,000 grant.

- NHS Ayrshire and Arran (Crosshouse Hospital)
- NHS Lanarkshire (Wishaw General Hospital)
- NHS Western Isles (Western Isles Hospital, Stornoway)

Each of these hospitals presented detailed plans to improve the care given to parents following the death of a baby. We look forward to seeing the outcomes of these projects in the coming years.

#### **Elaine Thorp Bereavement Care Award**

Elaine Thorp was an advocate and promoter of bereavement care training, and this Award honours her memory and her work by giving midwives and student midwives an opportunity through dedicated time to develop their knowledge, insight and understanding of good bereavement care following a pregnancy loss or when a baby dies. The 2016 award went to Michelle Powell, of Shrewsbury & Telford Hospitals NHS Trust.



# National audit of bereavement care in maternity units completed

#### **Bereavement care in UK** maternity units 2016: A snapshot Bereavement care for parents who experience the death of a baby continues to be highly variable across the country. Sands' recent survey of maternity units suggests that many Trusts and Health Boards across the UK continue to lack resources to provide the level of care that bereaved families need. of maternity units do not have a n only **46**% 1in3 Trusts and Health Board do not have a dedicated bereavement room in each maternity Sands groups help to When Trusts and Health fund the creation of Boards need to translate information for parents: and improvements to at local hospitals. 1in10 Trusts and Health Boards have no dedicated rooms at all. Health Boards across the UK, covering at least 364,216 deliveries, 1453 stillbirths and 543 neonatal deaths in © Sands 2016. Registered as a charity in England and Wales (299679) and in Scotland (SC042789) It is crucial that Trusts and Health Boards have the right A company limited by guarantee registered in resources and policies in place to ensure bereaved parents receive England and Wales number 2212082. the personalised care they need, and that staff are properly trained and supported to be able to provide this. f/sandscharity @SandsUK

We completed an in-depth audit of bereavement care provision in maternity units across the UK, which was published in January 2017. Survey responses were obtained from 79 trusts and health boards across the UK, covering at least 364,216 deliveries, 1,453 stillbirths and 543 neonatal deaths in 2015.

The findings of this audit suggest that many trusts and health boards across the UK continue to lack resources to provide the level of care that bereaved families need. This information will feed directly into our future campaigns to improve bereavement care for parents.

# Sands midwifery teaching materials developed

We joined with the University of Middlesex to produce high quality, up-todate teaching materials on issues related to be eavement.

The materials have been specially designed for teachers working with

student midwives and are a key part of our work to improve the bereavement care that parents receive by ensuring that high quality training is available.

So far 32 teachers have received the materials at institutions across the UK.

# Maternity Bereavement Experience Measure (MBEM) developed (for June launch)

Alongside NHS England and the London Maternity Clinical Network, Sands is a key partner in the Maternity Bereavement Experience Measure (MBEM) Project (formerly the Women's Recorded Experience Measure Project).

The MBEM aims to create an appropriate mechanism to give parents whose baby has died the opportunity to give feedback

about the bereavement care they received. In December 2016 Sands ran a detailed survey which gathered high quality data from **450** respondents as to what this mechanism should include.

This information will help to shape the MBEM and ensure the parent voice is paramount throughout the project.

Unfortunately on a daily basis I witness the devastating impact that the death of baby causes. Therefore I am passionate to help find ways in which we can improve care and outcomes both locally and nationally.

I believe by both health professionals and large organisations such as Sands working together and supporting each other we can achieve these improvements.

We frequently invite Sands to attend our multidisciplinary Bereavement Midwife Forum where we discuss obstacles in practice and best practice tips alongside potential improvements, as well as asking Sands to assist us in providing training to staff at both sites.

Lauren Hutton, Bereavement Midwife at both Queen Charlotte's Hospital and St Mary's Hospital I have used my personal experiences in practice to inform Sands of potential improvements in care, have provided feedback regarding new and current developments and have helped to source feedback from focus groups of bereaved parents e.g. bereavement care training for professionals, the development of training for Interpreters, and questionnaire feedback for the Maternity Bereavement Experience Measure.



### **RAISING AWARENESS**



#### 2016 successes

- 25 partner charities including Sands (10 new partners since 2015)
- Representatives from the charities attended an All-Party Parliamentary reception on Baby Loss at the House of Commons in London
- MPs from all parties, including Leader of the Opposition, Jeremy Corbyn, wore a pink and blue Baby Loss Awareness Week ribbon badge on their lapel during Prime Minister's Question Time
- We sold over **15,300** ribbon badges (vs. 8,600 in 2015, **44%** increase)
- Many buildings lit up in pink and blue
- BLAW received over 35 mentions in national and local media
- Developed a new website specifically for Baby Loss Awareness Week www.babyloss-awareness.org

# Baby Loss Awareness Week (BLAW)

Taking place annually from 9-15
October, Baby Loss Awareness Week is an opportunity for bereaved parents and their families and friends across the world to unite and commemorate their babies' lives; to raise awareness about the issues surrounding pregnancy and baby loss in the UK; to let the public and key stakeholders know what baby charities are doing to reduce the number of families affected; and to raise awareness about the help and support available.

# Social media activity and engagement during BLAW



- -2,640,862 Facebook reach
- **2,404** photos of candles added during and after Wave of Light



- #waveoflight trended all night on 15 October
- **258,400** reach during BLAW
- -2,000 retweets during BLAW
- **2,200** likes during BLAW
- 2.8% engagement rate during BLAW (this means a click on the tweet, retweet, like, etc. 2.8% is really strong!)

#### Other

**20,600** individual users on the Sands website (**20% up** on 2015)

A total of **51** tweets were posted on our Twitter page during the storyline, which meant three messages appeared during each episode. These ranged from contacting our Helpline, memory boxes to hold precious keepsakes including hand and footprints, to advice for bereaved grandparents.

Since Baby Loss Awareness Week started, more and more charities have come together that are committed to raising awareness of the issues surrounding pregnancy and baby loss, and working for change to reduce the number of families affected each year in the UK.

Dr Clea Harmer, Sands Chief Executive

### **Coronation Street**

The production team at the popular ITV soap *Coronation*Street asked us for our help and expertise on how to portray a storyline on late miscarriage accurately. We were happy to advise on the scripts to ensure that Michelle and Steve's heartbreaking scenes when baby Ruairi died were played sensitively. Our media team worked with their counterparts at ITV to ensure the local and national media were made aware of the story, which helped to raise awareness of the

devastating impact on parents and families when a baby dies.

Sands' name was mentioned
333 times in the media,
including every national daily
newspaper, TV, radio and national
print magazines including OK! and
Closer. Our experts also appeared
live on the ITV lunchtime
news and on popular daily TV
programmes such as The Victoria
Derbyshire Show. Due to the huge
media interest in the story, the
charity reached millions of people

who ordinarily and otherwise wouldn't have known we existed.

We extended the hours of our Freephone Helpline throughout the storyline so our bereavement experts were available out of hours to answer calls and emails from anyone affected by Michelle and Steve's story before, during and several hours after each episode was broadcast. Contact details for the Sands website and Helpline were posted on the ITV website.

For a TV drama like *Coronation Street* to cover this devastating experience was a brilliant way of raising awareness of the issues surrounding a baby's death at any gestation. Many people shy away from the issue; others have a misconception that this is a thing of the past. With *Coronation Street* covering this heartbreaking experience, it has helped to lift the taboo and raise awareness of all the issues that surround the death of a baby.

Erica Stewart, Sands Bereavement Support and Awareness Specialist





### Coronation Street in numbers



35,300

The number of people who clicked on the *Coronation Street* press release page on the Sands website



209

The number of people who contacted the Sands Helpline who said they were affected by the storyline



86

The number of times our chief executive, Clea Harmer, was quoted in the media before Michelle's attempted suicide after the death of her baby

# Sands Awareness Month: Walk A Mile In My Shoes



Our amazing fundraisers really went the extra mile to help support our vital work and we plan on developing this new fundraising initiative going forwards.

Several hundred walkers of all ages from across the UK joined their friends, family and colleagues and took part in the popular *Walk A Mile In My Shoes* event, where they asked people to make a donation in memory of their precious babies.

### Sands' mentions in the media

202
National

press

Regional

press

7

TV

**23** 

Radio

19

Trade / Consumer articles

TOTAL MEDIA MENTIONS 1,048

### Social media annual figures



Facebook



8,929

new followers

**13.7 million** reach

### Sands new website

Throughout 2016 we worked to develop the Sands website to ensure it presents Sands for what we are: the leading stillbirth and neonatal death charity in the UK.

We have achieved a more positive user experience through improved navigation:

- Bereaved families are able to access support more quickly and more easily
- Healthcare professionals have clearer access to the large number of materials available to better equip them to provide the best possible care

#### **Updated key features:**

- Easier to find through the revision of the URL to www.sands.org.uk
- Optimised for mobiles
- More personable approach through creation of a blog

316,935

website visits (up from 290,330 in the previous year)

**72%** of which were new visitors

In 2016 one inspiring fundraiser, Adam
Leyton, set off with a mission to beat a world
record by visiting 12 countries in 24 hours
using only scheduled/public transport.

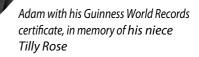
Adam chose Sands because over seven years ago his sister Gemma lost her baby daughter Tilly Rose just five days before she was due to

hours by scheduled transport is 12 and was achieved by Adam Leyton be born. "The support Sands gave to my sister and her family was incredible. This was my way of saying thank you to them."

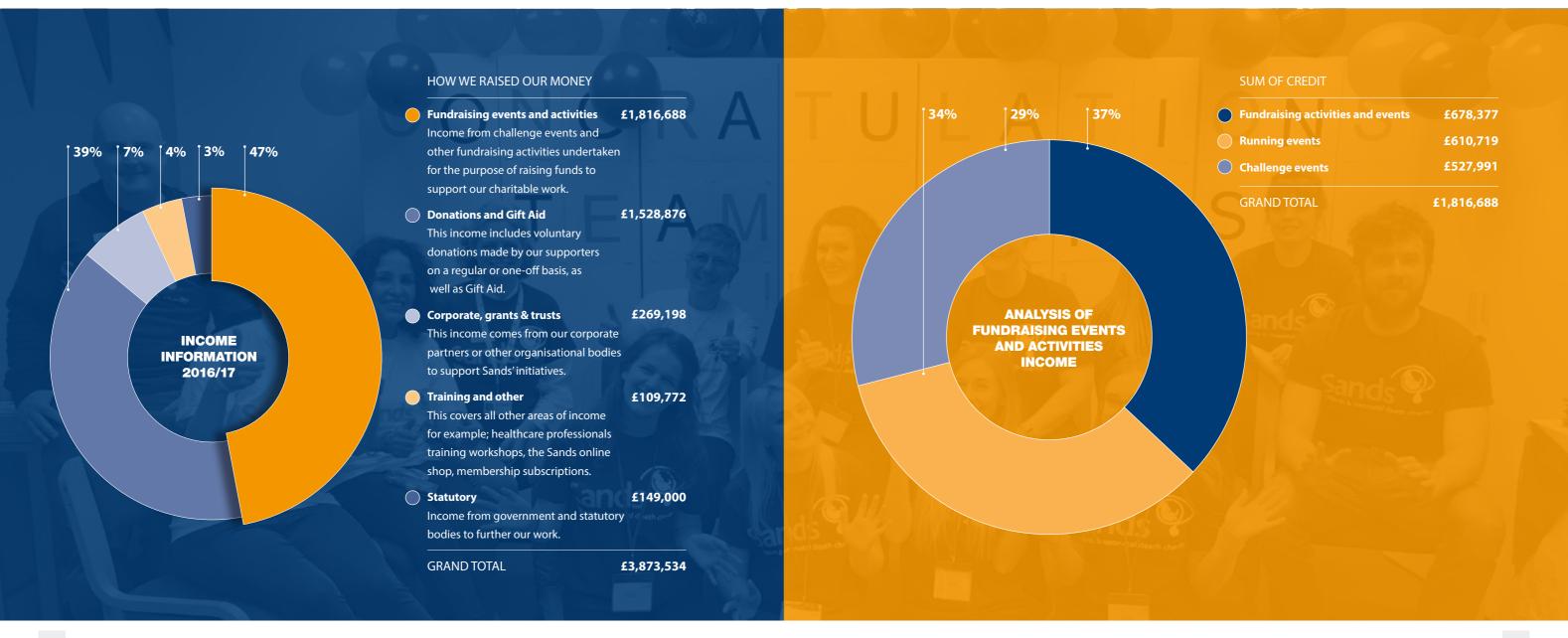
Not only did Adam raise an incredible amount for Sands, his achievement was officially recognised and he became the Guinness World Records Title Holder for such a feat!

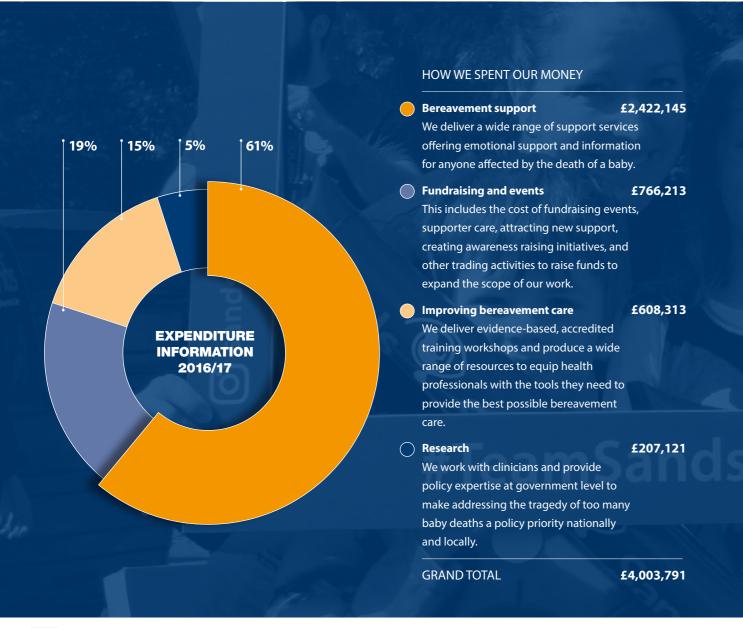
It was an incredible adventure. I beat a world record, raised a huge amount for Sands and hit the news media headlines in 35 countries across

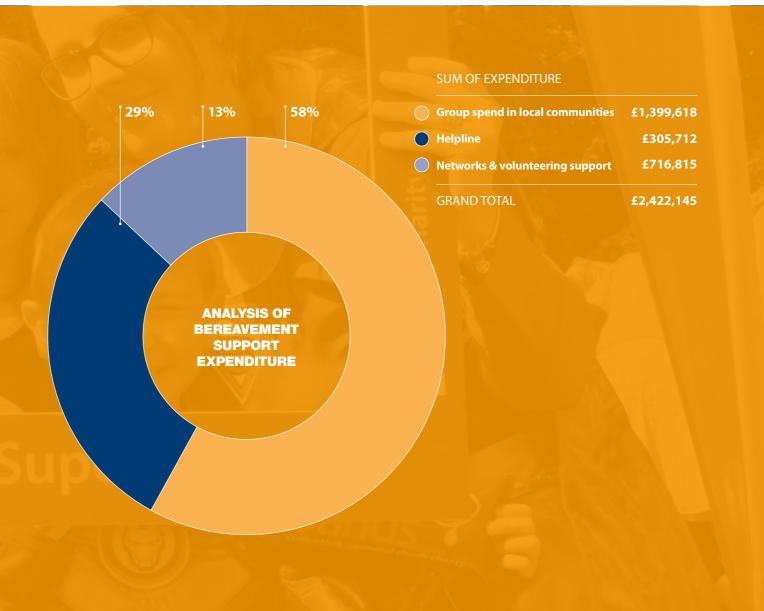
4 continents.



### **FINANCIAL REVIEW**







# FUNDRAISING AND VOLUNTEERS: A HUGE THANK YOU

Everything we achieved this year wouldn't have been possible without the thousands of people who fundraised and organised events to raise money for Sands.



A big thank you to everyone that literally **gifted hundreds of hours** of their precious time to knit, crochet, support, cheer, listen, speak, share, tweet, engage, promote, and volunteer for Sands.

And last, but by no means least, a huge thanks to the following corporate partners, trusts and foundations for your generous support:

- Aldermore Bank PLC
- ASCO UK Ltd
- Aspect Capital
- Aurum Charitable Trust
- Begbies Traynor
- Berry Brothers and Rudd
- Cope Safety Management
- DHL Supply Chain
- Dot Zinc Limited
- Greenwood Campbell
- haysmacintyre
- Hogg Robinson Group Plc
- Horizon Discovery
- Lakeside North Harbour
- Leslie Clark Construction
- LogRhythm
- Lombard

- My Sales My Lets
- Sainsbury's Food Commercial Division
- Scorpio Worldwide
- Siemans Poole
- Southwater Events
- Spar Limited
- St. James's Place Foundation
- Sunnybrook Health Sciences Centre
- Synectics Solutions
- Sytner Group
- Teddy's Wish
- The Mitchell Charitable Trust
- The Pamela Champion Foundation
- The Sir James Reckitt Charity
- Trapeze Group
- Turtle Tots Scotland
- Whale Tankers Limited



Tom Stock (centre, front row) with his colleagues from haysmacintyre having completed the London Triathlon in aid of Sands

Sands was nominated and chosen as haysmacintyre charity of the year in March 2016 by one of their employees, Tom Stock, who had received support from Sands following the loss of his daughter Millie, who was stillborn in August 2015.

As a firm we've really enjoyed coming together to raise money for Sands. The events we've enjoyed have been varied and meant that there has been something to suit all tastes – from the in-house lunches and raffles, to more active sponsored events such as the London Triathlon, everyone has got involved and supported our efforts.

Most importantly we've together raised a great amount, totalling almost £7,000 in a year, to help fund Sands' important work and support for bereaved parents and families. We're really proud of our achievements and are looking forward to our second year of supporting Sands.

...working together to improve outcomes for families



#### **Enquiries:**

t: 020 7436 7940

e: info@sands.org.uk

#### **Support:**

**t:** 0808 164 3332

e: helpline@sands.org.uk

#### www.sands.org.uk

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/sandscharity

in /company/2954113

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