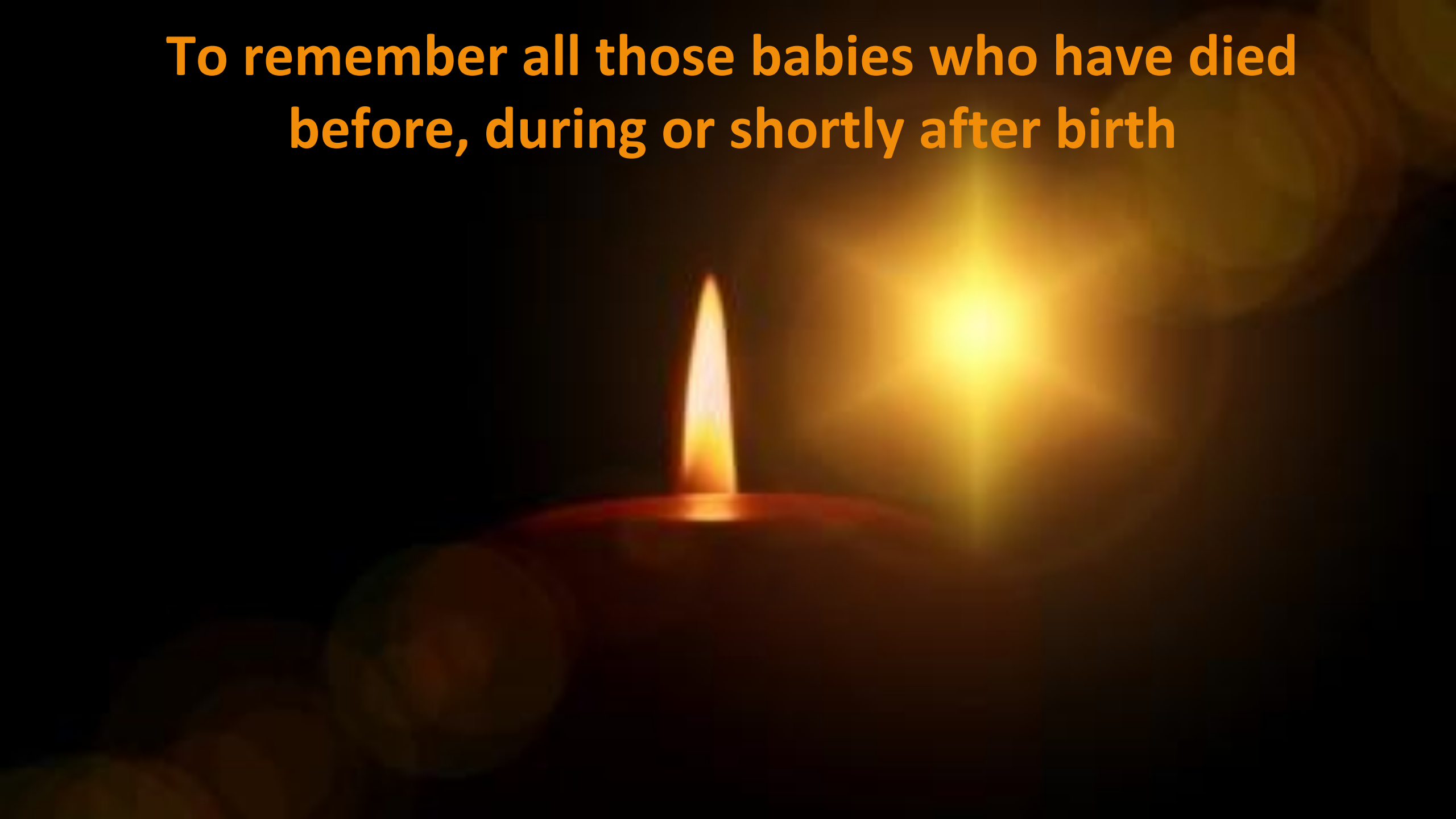




# #FindingYourWay Conference

23rd November 2019  
Resource for London

**To remember all those babies who have died  
before, during or shortly after birth**



# Welcome and introduction



**Clea Harmer**  
*Chief Executive*

Sands #FindingYourWay Conference



# #FindingYourWay Conference

## Spotlight on Sands #FindingOurWay

23rd November 2019  
Resource for London







**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.**

## Spotlight on the work of Sands as we:

- ▶ Help **save babies' lives**
- ▶ Ensure excellent **bereavement care** for all those who need it
- ▶ Provide the right **bereavement support** for as long as it is needed

## Spotlight on some of our 'enablers':

- ▶ **Raising awareness** of the issues relating to stillbirth and neonatal death
- ▶ **Collaboration** with others to make more of a difference
- ▶ **Culture** of growth and hope



# Finding Our Way to make a difference

What is unique about Sands' Way of making a difference?

- ▶ The **voice of bereaved parents** is at the heart of all we do
- ▶ Our **3 core aims** - saving babies lives, improving bereavement care; supporting anyone affected by the death of a baby
- ▶ **Our values**

Compassionate

Collaborative

Evidence-based



**Groups  
and  
Volunteers**



**Supporters  
and  
Fundraisers**



**Staff**

**Those we  
work with**

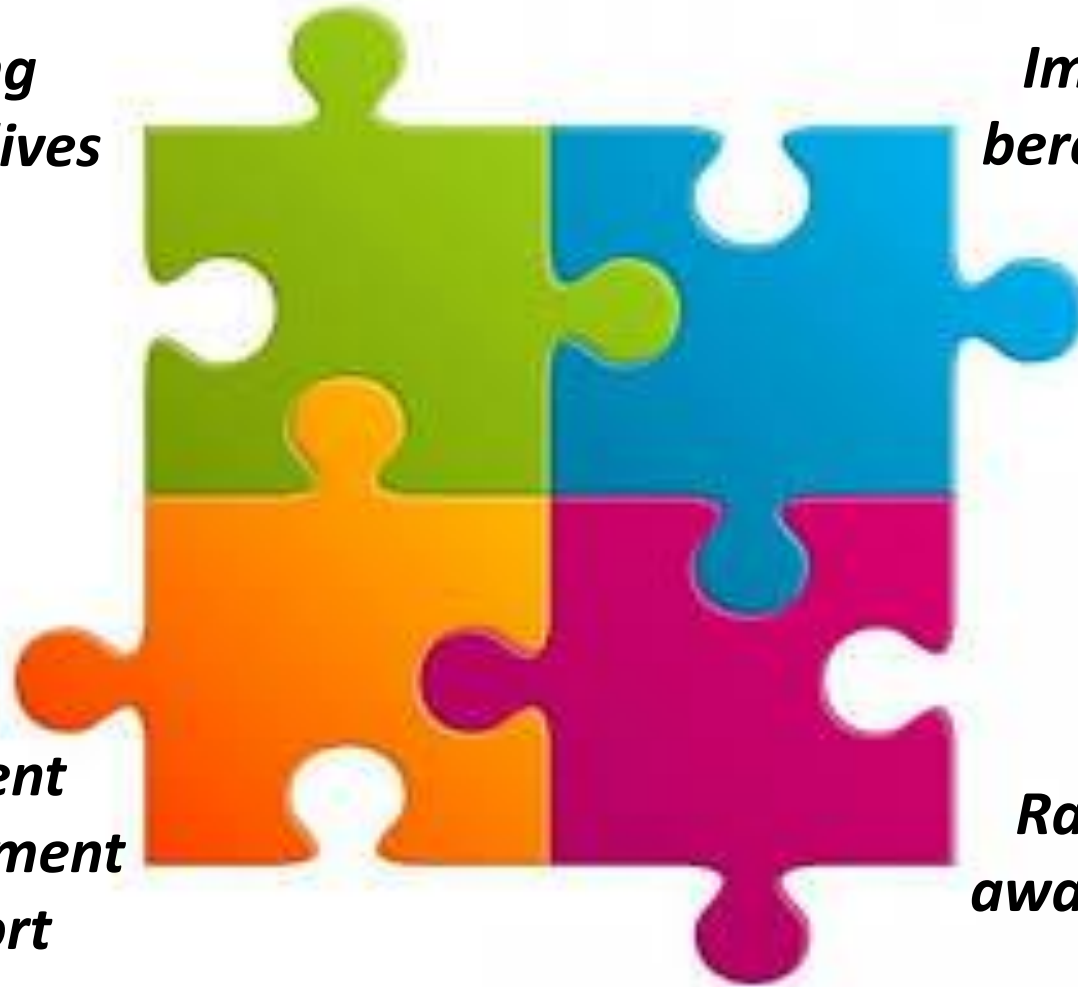


***Saving  
babies lives***

***Improving  
bereavement  
care***

***Excellent  
bereavement  
support***

***Raising  
awareness***



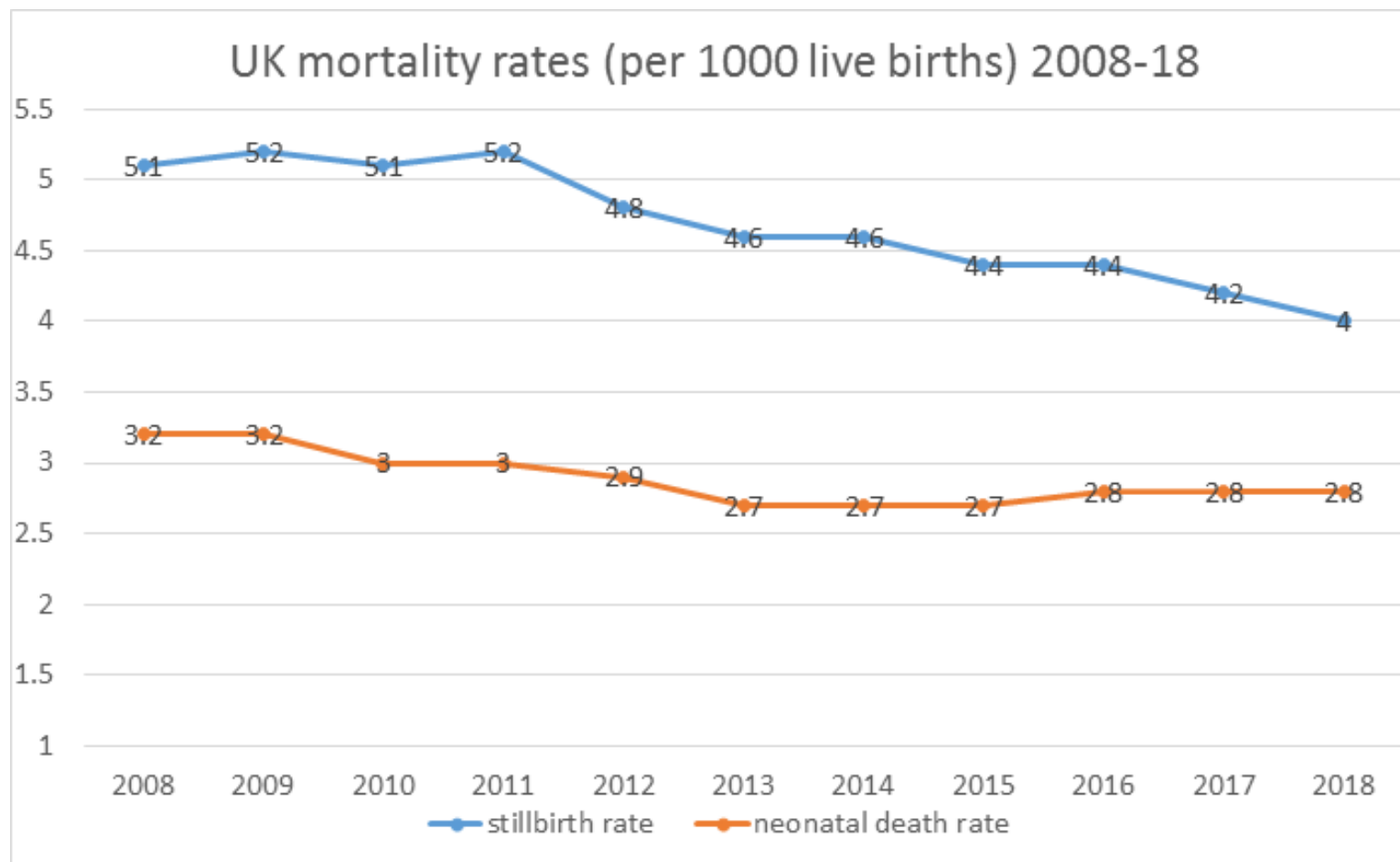
# Finding our way to **save babies lives**

New data based on 2018 registration figures

- ▶ 2,958 babies were stillborn
- ▶ 2,028 babies died in first 4 weeks
- ▶ 4,986 stillbirths and neonatal deaths
- ▶ **14 babies a day in 2018**

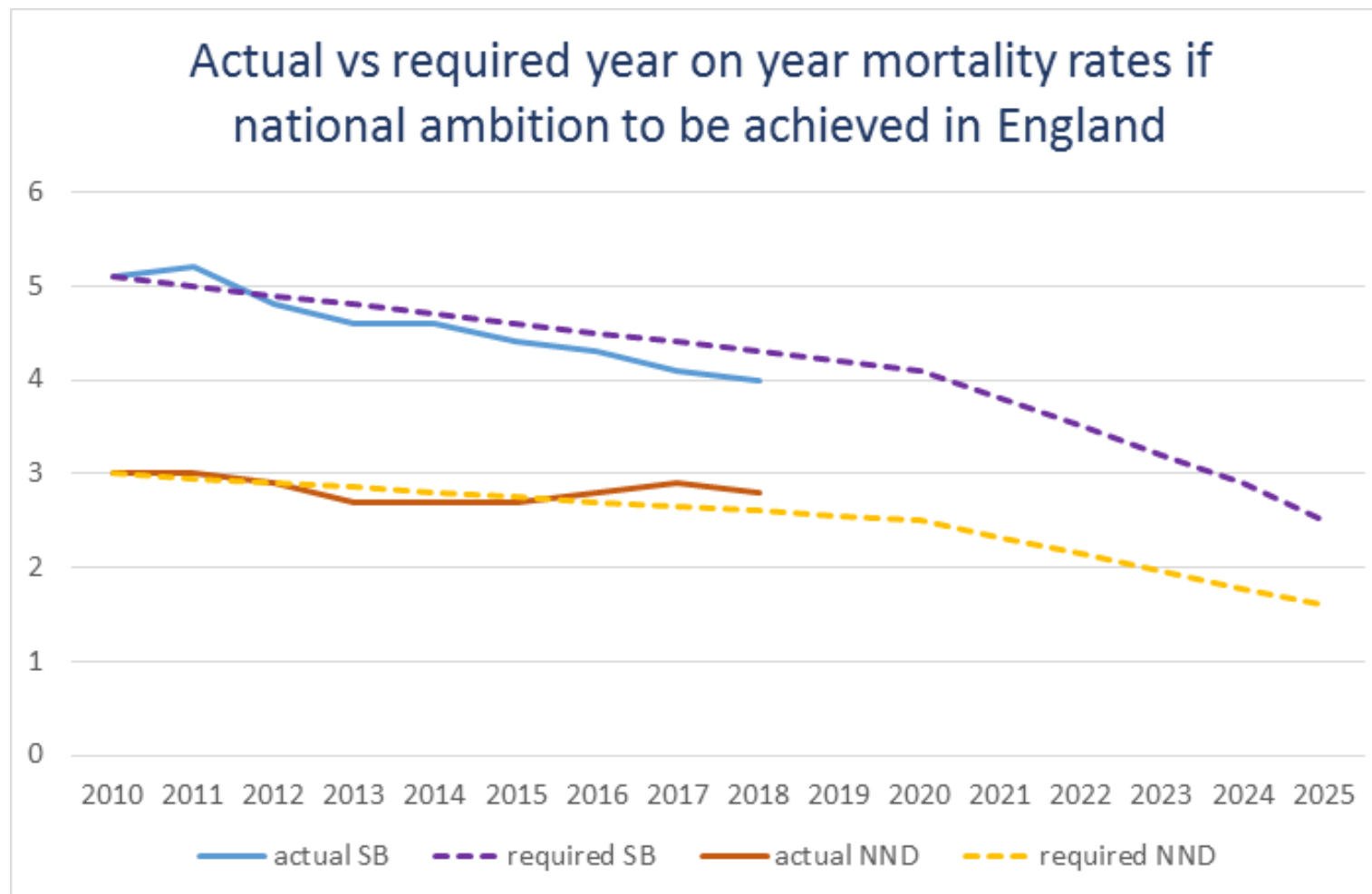
**345 fewer baby deaths in 2018 than in 2017**

# Finding our way to **save babies lives**





# Finding our way to **save babies lives**



# Finding our way to **save babies lives**



Understanding  
why babies die



Using  
knowledge to  
inform practice



Raising  
awareness



# Understanding why babies die

- ▶ Research
- ▶ Review

*As parents we want desperately to know what happened, even when the truth is difficult. After all we've already experienced the worst*

*We want to know that things will be better for the next parents whose labour and birth are like ours*



## Research: What Sands uniquely brings

- ▶ We represent the voice of bereaved parents
- ▶ We have both convening power and national influence
- ▶ We can ensure research is translated into practice



# New Research Strategy

- ▶ Enable bereaved parents to inform and shape research





For more information, visit  
[sands.org.uk/research](https://sands.org.uk/research)  
and follow #SandsResearch



### Sands-funded projects

#### Inequalities in stillbirth: a meta-narrative review

This project has been designed in response to the need to do more to prevent stillbirth among women identified as...

#### Outcome of resuscitated term babies with no heart rate detected at 10 minutes of age

This study aims to identify babies born at term (at the end of a full-length pregnancy) in the UK and...

#### Parents and Neonatal Decisions Study

This research is designed to improve the way doctors talk with parents about the decision whether or not to start...

#### Prediction and prevention of perinatal death

This project aims to find a way of identifying babies at high risk of death in the womb or shortly...

#### The Pregnancy Outcome Prediction (POP) study

**AFFIRM** – can promoting awareness of baby's movements in pregnancy help reduce stillbirths?

# New Research Strategy

- ▶ Enable bereaved parents to inform and shape research
- ▶ Grow collaborations of research excellence
- ▶ Support key research that will make the greatest difference to our objectives
- ▶ Improve maternity, neonatal and postnatal care
- ▶ Increase the profile of, and funding for, all perinatal mortality research

# Review: involving bereaved parents

## ► For professionals – opportunity to learn

- Parents' experiences and perspective may add to the clinical picture and drive improvements in care
- Parents are the only people there all the time



## ► For parents – understanding what happened

- Knowledge that their experiences can be used to ensure others do not have to go through what they have been through

# Reviews and bereavement care

- ▶ Involving parents in reviews is good bereavement care



# Are parents voices being heard?

## PMRT Report – parent engagement

- ▶ 84% told about review
- ▶ 75% parent perspective sought

## Clear improvement from:

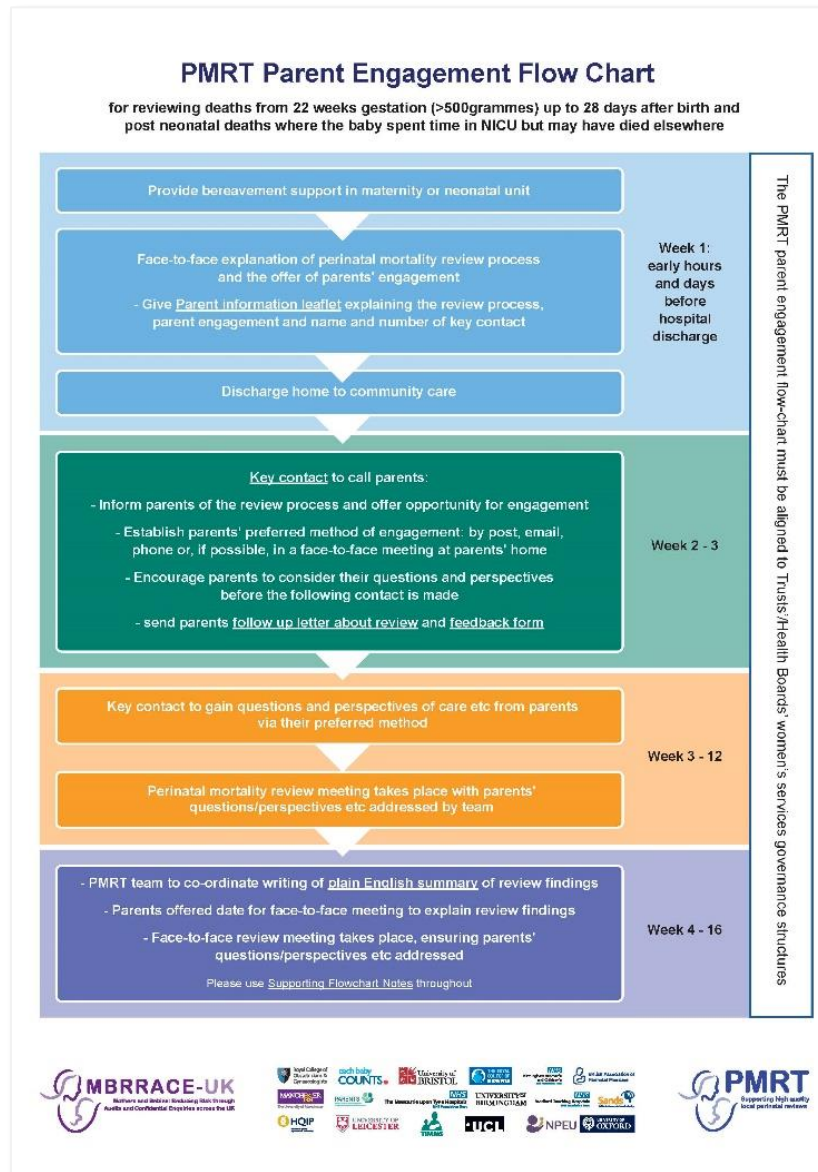
- ▶ MBRRACE 2013 – 20%
- ▶ Each Baby Counts 2016 – 41%





... but how easy is it to contribute ?



# PMRT Parent Engagement Flow Chart



## PMRT Parent Engagement Flow Chart Notes

Trusts and Health Boards should ensure the PMRT parent engagement process is aligned with their women's services governance structures

**Week 1**

Face-to-face discussion with parents about review before discharge should be with a senior member of staff, and NOT a junior staff member. For example, a consultant or experienced member of the Bereavement Team.

Discussion before discharge should be accompanied with written information Parent information before discharge.

Key contact should have appropriate skills and training Key Contact Responsibilities

Key contact to make parents aware of working days and availability.

Perinatal Mortality Review Lead to organise admin support for key contact.

If there are likely to be other investigations on-going such as a report to coroner/procurator Fiscal, an HSB investigation or SAER ensure parents are made aware of the difference between these and the PMRT hospital review and how these will be co-ordinated.


**Week 2-3**

If, after discharge, parents cannot be reached after 3 phone/email attempts, send When parents cannot be reached letter informing parents of the review process and inviting them to be in touch with key contact, if they wish.

If causes for concern for the mother were raised during her pregnancy consider contacting her GP/primary carer to reach her.

If communication challenges are anticipated (such as in cases of domestic violence, where there are cultural sensitivities, or there may be information gatekeepers) try to speak to woman directly.

If parents do not wish to input into the review process ask how they would like findings of the perinatal mortality review report communicated to them: by post, email, telephone call or in a face-to-face meeting. Parents may want more than one form of communication.



ed to both parents if known, and multiple pregnancy. Letter to

Feedback form neonatal death is multiple pregnancies where one or

es.

If possible,

mail or online links - make these

questions and perspectives of

uring any delays, such as findings communicated to parents by email

: may also want to telephone

at other con-current

coroner or procurator fiscal

report; ensure parents are made

ot delay routine clinical post-natal

ke place as normal.

it by 16 weeks. Parents should be

formed that results of review may

o ensure language summarising

primary/letter ahead of meeting

in.

should be conducted by a senior

representatives of the neonatal and

# Template parent information, letters and feedback forms

[Template 'Parent information before discharge']

*Insert hospital logo*

## Understanding what happened – hospital review

We are sorry that your baby has died. We understand that this is a difficult time to be reading new information.

It is important to understand as much as we can about what happened and why your baby died. In order to do this, in the coming weeks a hospital team at *[insert Trust/Health Board name]* will hold a meeting and review your and your baby's/babies' *[delete as appropriate]* care.

**The review will:**

- look at medical records, tests and results, including post mortem results if you have consented to one
- answer any questions you may have and address any concerns
- talk to staff involved
- look at guidance and policies to ensure the care you received was appropriate

The review may tell us that we need to change the way we do things or that good and appropriate care was given to your family.

**Involving you**  
Your views are important and it would be helpful if you could share your feelings and thoughts about your care, or any questions you have with us before we carry out the review. To support you in doing this, we have provided you with a key contact:

*Insert name and contact details of the key contact*

**Your key contact will:**

- call you to talk to you about the review process

*Insert hospital logo*

## Feedback Form for Parents

This form is designed to help you think about any questions or comments you may have about aspects of your and your baby's care. You do not have to use this form or limit yourself to the spaces in this boxes. The form is just a way of triggering your thoughts.

Any feedback you give us will help the hospital team to review your care and ensure we address your questions as best as we can.

You can post the feedback form back to us, using the self-addressed envelope, call us to discuss your questions or concerns, using the details of your contact. You can also access the form online at *[insert link]*.

**Care during pregnancy**

- Please use this section for comments on and questions about the care you received during your pregnancy.

**Care during the birth of your baby**

- Please use this section for comments on and questions about the care you received when you were in labour and when your baby was born.

Please use this section to include other medical services and support services.

If you would like to comment on the support you received here.

Please use this section to:

Are there any other comments you'd like to make?

# Finding our way to ensure excellent bereavement care for all

Whilst no level of care can remove the grief that many parents will feel, good care can make a devastating experience feel more manageable while poor quality or insensitively delivered care can compound and exacerbate the pain.



# National Bereavement Care Pathway: the parents' voice at the heart of the pathway

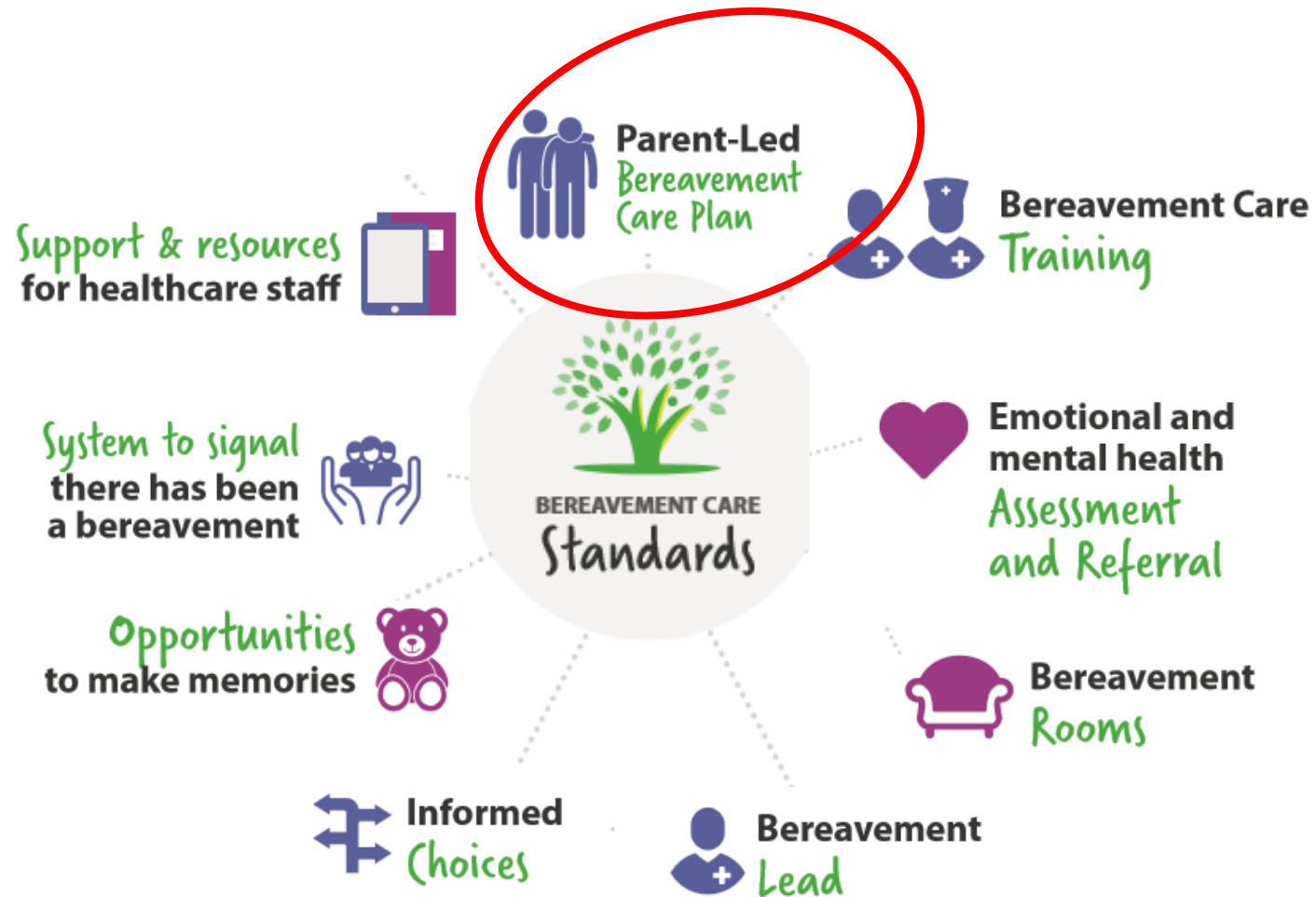
Equal and excellent bereavement care for all parents whenever and wherever their baby dies

## Parent Workshops and Parent Advisory Group

- Communication is key
- There should be continuity and consistency in care
- Parent-led family involvement is vital

NBCP describes multidisciplinary care that meets the 9 Bereavement Care Standards at any point which touches the parents' grief journey

# Bereavement Care standards





*The hospital was amazing at comforting me and my partner during the birth of our son... they were also very gentle with him once he was born which was a main concern of mine, we both felt our son was well taken care of and so was I. We cannot thank all the staff that dealt with us enough*

# Rolling out NBCP across all NHS Trusts

## In England (143 Trusts)

122 Trusts engaged (49 active sites)

## In Scotland (14 Health Boards)

5 Adopter sites

## In Wales (7 Health Boards)

Hospitals expressing interest – self assessment/guidelines etc. available

## In NI (6 Trusts)

Revising guidelines

## Registering your NHS Trust's interest

32 NHS Trusts in England have piloted the NBCP and we are working hard to encourage all other Trusts to adopt the pathway in 2019 and 2020.

The sign-up process has three steps:

1. Register your interest by clicking the button at Step 1 below. Any NHS Trust employee can do this
2. Complete and return the relevant information requested in the introductory pack. The pack will be sent to you once your interest has been registered. A lead employee will need to be identified to complete this on behalf of the Trust
3. Confirm your Trust has signed up by filling out the form at Step 2 below. A designated signatory must confirm in writing to the NBCP project team, at which point the Trust will be assigned 'NBCP adopter' status and published on the NBCP current adopters' [webpage](#)

### Step 1. Express your interest

Complete this simple form and we'll email you with access to our 'How it works' Toolkit where you can learn more about the NBCP project, share it with your team and decide if it's right for you.

Yes please, tell me more  
about the project

### Step 2. Sign up to the project

If you decide you'd like to get involved, let us know by filling out this quick form and we'll get you started.

I'd like to take part, sign  
me up



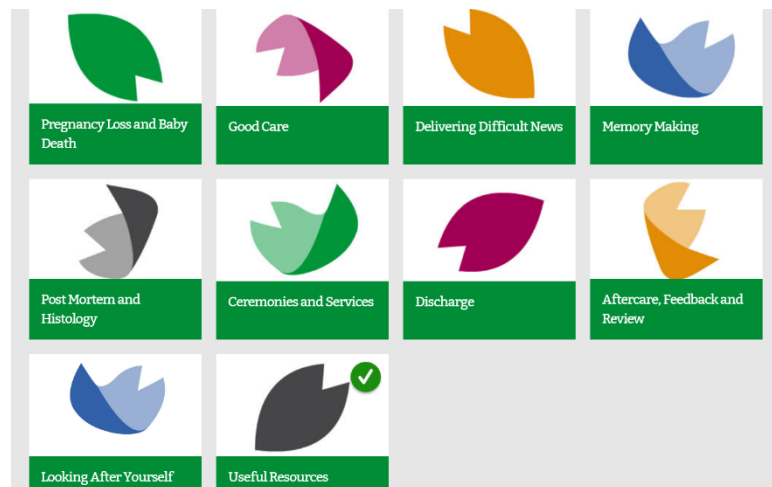
[nbcpathway.org.uk](http://nbcpathway.org.uk)



# NBCP – online learning modules

[www.e-lfh.org.uk /programmes/national-bereavement-care-pathway](http://www.e-lfh.org.uk/programmes/national-bereavement-care-pathway)

- ▶ 10 minute introduction module for everyone
- ▶ 30 minute module for healthcare professionals



# Consultancy

What Sands can offer employers:



# Further work to improve bereavement care

- ▶ **Developing training further**
  - Enhanced workshop aimed at experienced practitioners
- ▶ **Audits of care**
  - Maternity units (2017)
  - Neonatal units (2018)
  - Gynaecological units (2019)

# Bereavement care and ongoing bereavement support

- ▶ Ensuring parents can access the bereavement support that they need once they leave hospital is crucial



[www.sands.community](http://www.sands.community)

**1,059** bereaved parents joined the online community in 2017/18



# Finding our way so that **bereavement support** is available where and when it is needed

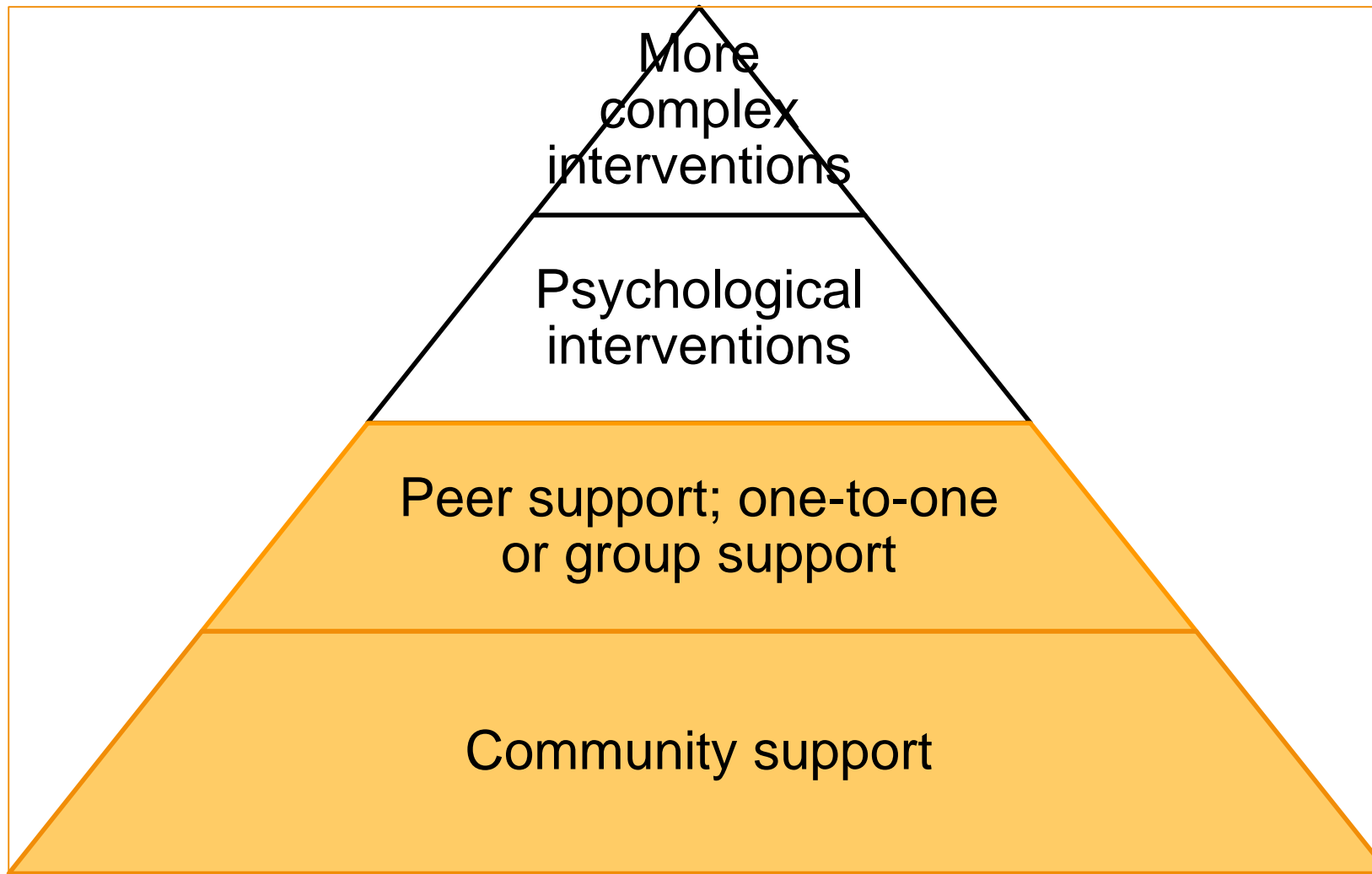
*My life has changed completely. I am functioning, I'm not depressed, I work, I have a wonderful husband and lovely family, I am even happy again but I will never, ever, be the same person again.*





# Growth and hope

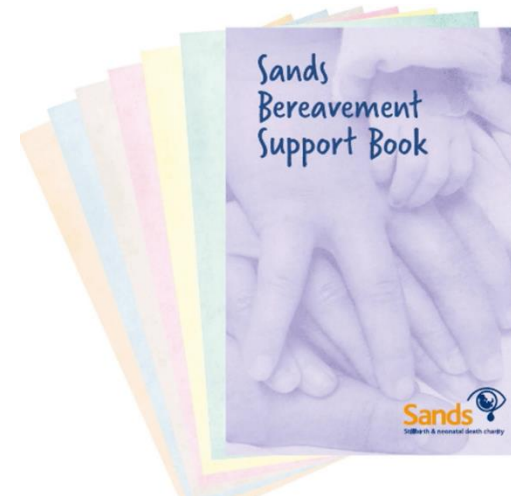




## Theory of bereavement support

# Making sure the right support is available

- ▶ Group support – befrienders
- ▶ Memory boxes
- ▶ Helpline
- ▶ Sands Bereavement Support book
- ▶ Online community
- ▶ Bereavement App



JUST PUBLISHED

## Sands Bereavement Support Book

Visit [sands.org.uk/book](https://sands.org.uk/book)

# Sands United

- ▶ Sands United – bereavement support and also an opportunity to raise awareness and funds



# Finding our way to raise awareness

## ▶ #Findingthewords

## ▶ #Findingyourway

**Find the words to break the silence around baby loss...**



**#FindingTheWords**

**Sands**  
Stillbirth & neonatal death charity

**40** 1978 2018  
years of support

**#FindingYourWay2019**

**Tackle the taboo and help break the silence around baby loss**

**Sands**  
Stillbirth & neonatal death charity

[www.FindingYourWay.org.uk](http://www.FindingYourWay.org.uk)

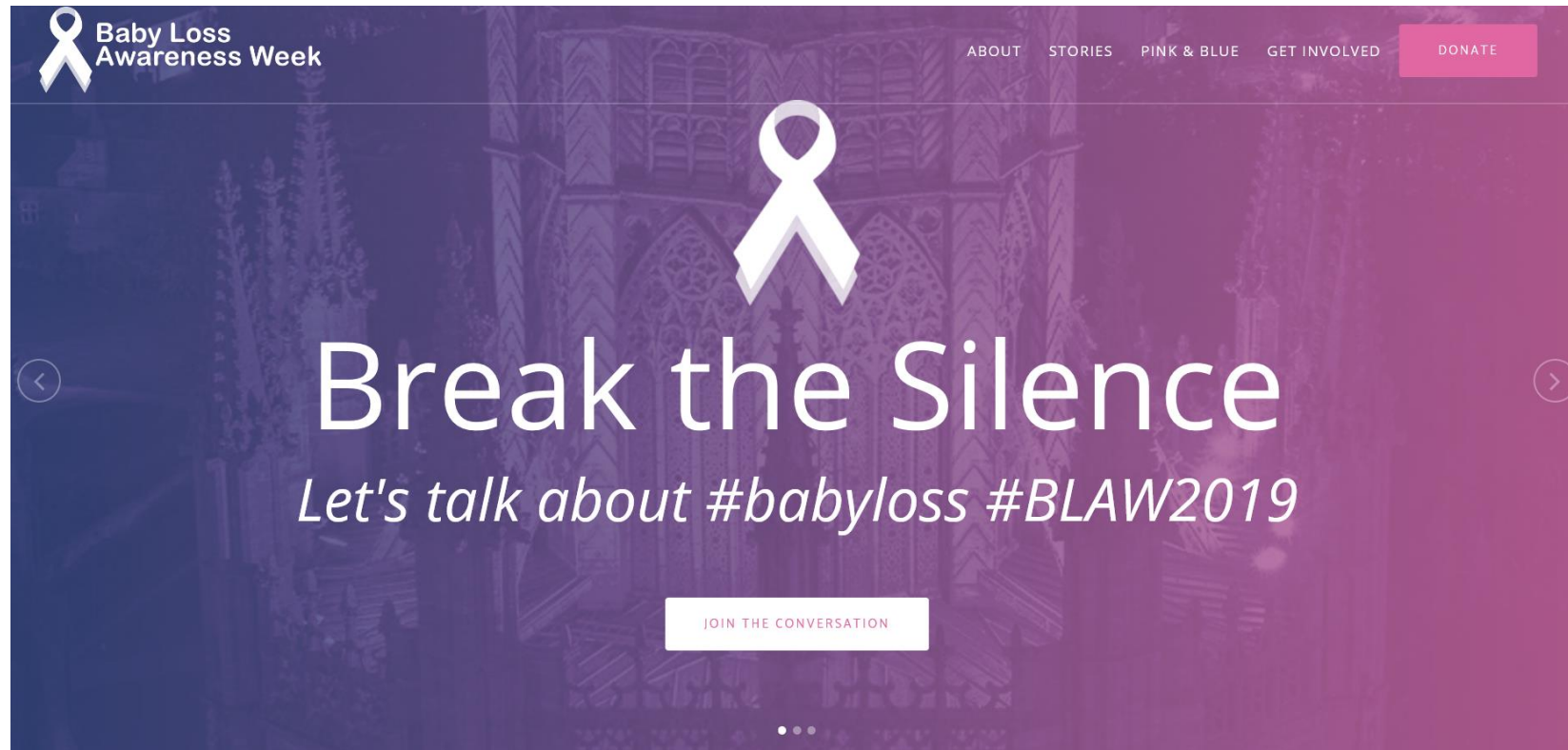
**Sands**  
Stillbirth & neonatal death charity



# Volunteers and supporters raising awareness



# Finding our way to raise awareness and collaborate





# The voice of bereaved parents: Baby Loss Awareness Week



Commemorate babies' lives and support bereaved parents



Raise awareness about pregnancy and baby loss



Drive change and improvements in care and support

# Commemorate babies lives

- ▶ Remembrance events
- ▶ Digital Photo Mosaic - #BLAW2019mosaic
- ▶ Wave of Light

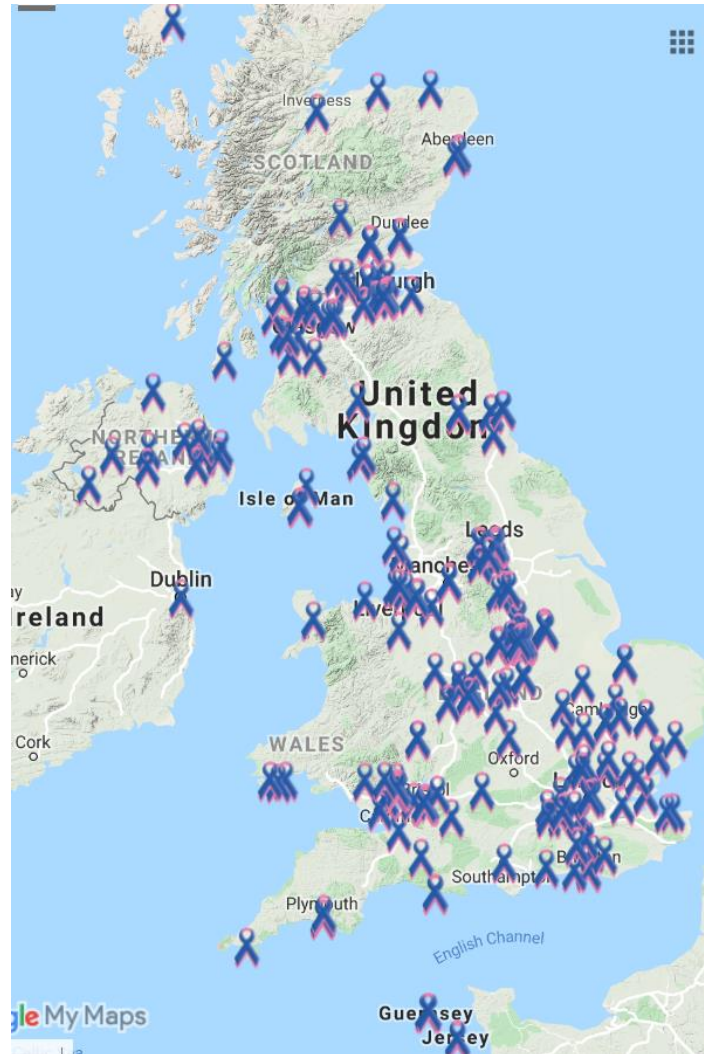




# Baby Loss Awareness Week 2019



267  
Buildings  
turned  
pink and  
blue





# Raise awareness

- ▶ Social media – Facebook, Twitter and Instagram
- ▶ Ambassador video
- ▶ Press and media
- ▶ Celebrity engagement

## Jools Oliver shares emotional post to mark Baby Loss Awareness Week

"A wave of light for all the families who have been affected by baby loss."

By Emma Nolan 16/10/2019



**Professor Lesley Regan**  
President, Royal College of Obstetricians and Gynaecologists



**Malin Andersson**  
Mental Health Advocate, Body Confidence Activist



her husband were told their daughter's heart had stopped beating at 35 weeks (State Ingress)

*I couldn't heal from baby loss until I had space to talk about it – I want the same for other women too*



What has soothed me is hearing other people's stories – both online and in person. Having a sense that you aren't alone in wrestling with such grief can be a huge comfort

**Catherine Anne Davies**  
Thursday 10 October 2019 14:18 |



eded for women who suffer with stillbirths and miscarriages. ( Getty )



## Stats from 9-15 Oct 2019



### Facebook

Total reach – 695k  
Followers gained – 1,929  
Total engagement – 44k

People reached  
increased by  
674%



### Twitter

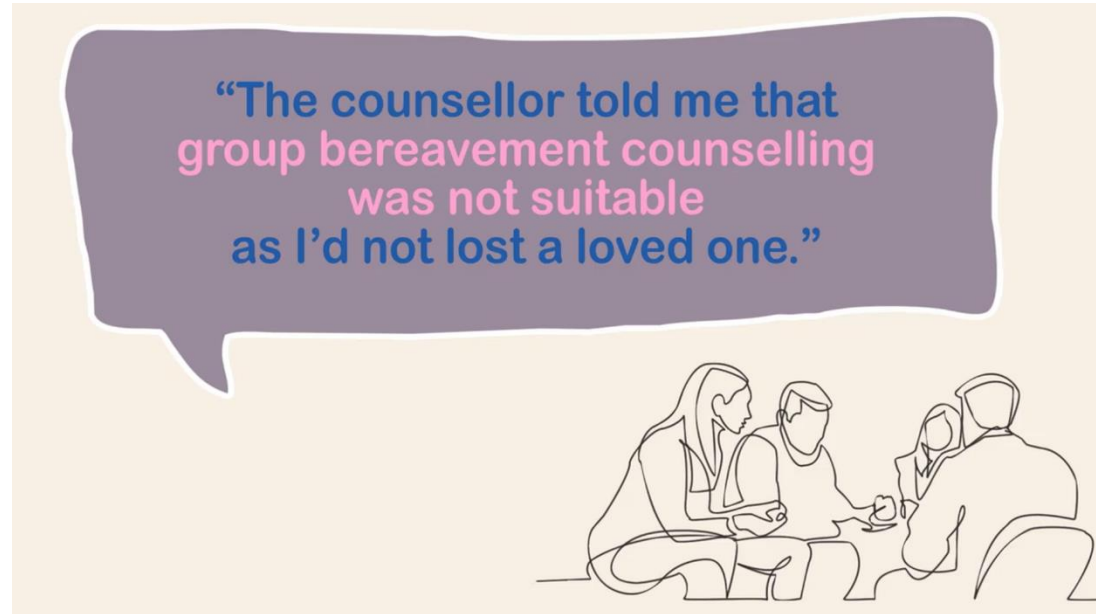
Total impressions – 244k  
Followers gained - 525  
Total engagement – 9,916



### Instagram

Total impressions – 383k  
Followers gained – 1,384  
Total reach – 20k

# Drive change



## Out of Sight, Out of Mind Report

All parents who experience pregnancy and baby loss and need specialist psychological support should be able to access it, at a time and place that is right for them, free of charge, wherever they live.



# Collaboration

- ▶ Pregnancy and Baby Charity Network
- ▶ One Voice
- ▶ Baby Loss Awareness Week
- ▶ National Bereavement Care Pathway



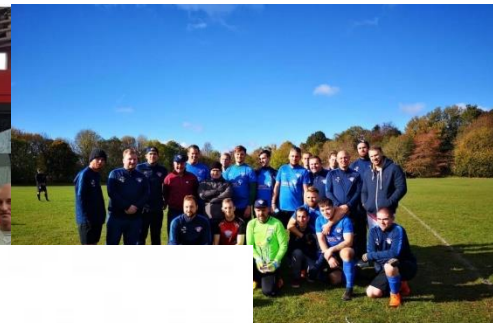
# Culture



## Finding our Way ....

- ▶ to make a difference – for parents now and for parents in the future







# Discover the impact of our work



See our latest  
Impact Report at  
[sands.org.uk/ourimpact](https://sands.org.uk/ourimpact)







**#FindingYourWay Conference**

**Final summary and close**

23rd November 2019  
Resource for London