

# OUT OF SIGHT, OUT OF MIND

Bereaved parents falling through the  
gaps in mental health care in England

A briefing by  
the Baby Loss Awareness Alliance



#BLAWOutOfSight

## 2. Introduction

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**This Baby Loss Awareness Week we are calling on the Government to take action to ensure that all parents who experience pregnancy or baby loss and need specialist psychological support can access it, at a time and place that is right for them, free of charge, wherever they live.**

Thousands of parents experience pregnancy or baby loss every year. It is estimated that :

**1 IN 4**

one in four pregnancies end in miscarriage <sup>1</sup>

**1 IN 80**

one in eighty are ectopic <sup>2</sup> and

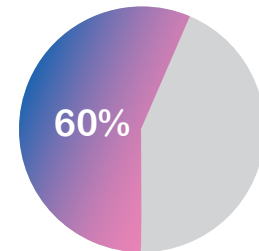
**15 BABIES  
A DAY**

are stillborn or die shortly after birth every day in the UK. <sup>3</sup>

Grief is a natural response to this particularly isolating bereavement. Some people carry this with them for the rest of their lives but do not develop a mental health problem. However, many bereaved parents will go on to experience psychiatric illnesses that require specialist support, triggered by intense grief and the trauma of their experience.

Information gathered by the Baby Loss Awareness Alliance shows that although there is a clear need for specialist psychological support for this group, too often it is unavailable, inaccessible or

inappropriate. Too many people who experience a psychiatric illness after their loss do not receive the support they need. They have been falling through the gaps between policy and funding, and are often overlooked altogether.



Across the UK 60% of bereaved parents told us they felt they

needed specialist psychological support for their mental health, but were unable to access it on the NHS<sup>4</sup>, and nearly nine out of ten Clinical Commissioning Groups (CCGs) told us they do not commission talking therapies specifically for this group, that both parents are able to access<sup>5</sup>.

9 OUT  
OF 10



“ After my baby died I felt I needed psychological support. I was referred and the support took place in the neonatal ward of the hospital where I gave birth to my dead baby. I had to sit in a waiting room each week while other people’s babies were wheeled past me. The psychiatrist who saw me informed me that my thoughts/grief were unhelpful and wrong and if I just “thought differently” I’d feel better.

(bereaved parent)<sup>6</sup> “

There is some emerging good practice in England, and with the current focus on improving mental health, and in particular perinatal mental health, there is an excellent opportunity to tackle this. Further work is needed to develop and evidence the solutions, and we are committed to working alongside decision makers to achieve this.

1. Tommy's - [www.tommys.org/our-organisation/our-research/research-miscarriage](http://www.tommys.org/our-organisation/our-research/research-miscarriage)

2. Ectopic Pregnancy Trust – [www.ectopic.org.uk](http://www.ectopic.org.uk)

3. Sands - [www.sands.org.uk/why-15-babies-day](http://www.sands.org.uk/why-15-babies-day)

4. Sands, Survey of Maternity and Neonatal Care, May 2019, sample size of 1,007

5. Baby Loss Awareness Alliance, Out of sight, out of mind: parents falling through the gaps in mental health care, October 2019, [www.babyloss-awareness.org](http://www.babyloss-awareness.org)

6. Sands, Survey of Maternity and Neonatal care, May 2019, sample size of 1,007

### 3. Progress since Baby Loss Awareness Week 2018

**The National Bereavement Care Pathway (NBCP) provides the framework and tools to ensure that all health <sup>7</sup> professionals are adequately equipped to provide excellent bereavement care during the immediate aftermath of pregnancy or baby loss.**

During Baby Loss Awareness Week 2018 we called for this to be embedded and rolled out across the NHS to ensure that all bereaved parents get the best possible bereavement care.<sup>8</sup>

Since then, the Prime Minister endorsed the final positive evaluation of the pilots in England, urging all NHS Trusts to adopt the NBCP, and roll-out across England has begun. Over 130 trusts have expressed

their interest so far. Work continues with the CQC, NHS England and other partners to embed the NBCP, and include it within their frameworks and guidance.

Although the provision of appropriate psychological therapies is not within the scope of the NBCP, the evaluation findings show this is a significant gap for bereaved parents that the government should take steps to address.

7. 'Perinatal' means the period of time covering pregnancy and up to around a year after giving birth.

8. Bereavement care is provided by health and social care professionals from the time a parent experiences a loss, or when it is expected the baby will die. It includes all communications with the parent, the care environment, resources and facilities

9. Improving Access to Psychological Therapies

## The current picture



To date perinatal mental health services have been focused on women who are pregnant or have a living baby, resulting in mothers whose baby has died often not meeting the inclusion criteria to access support. On the rare occasions that they are able to access perinatal mental health services, often they do not find them appropriate. For example, being invited to attend clinics surrounded by families with living babies.

87% of CCGs told us they do not commission a specialist service accessible to both parents who have experienced pregnancy and baby loss. While many informed us that IAPTs<sup>9</sup> should be available to them, this has not been reflected in their experiences. They tell us

that waiting lists are too long and that these services lack the specialist skills and knowledge to support them. Where services do exist they are mostly for mothers only, meaning partners' needs are also often overlooked. This is clearly unfair and inequitable - an unintentional oversight in the reorganisation of maternity and perinatal mental health care.<sup>8</sup>

There are exceptions to this. For example Petals, a specialist trauma-based counselling service, providing free support to women and couples who experience baby loss within 15 days of their loss. This is formally commissioned on the NHS in some areas of London and the South East. However, such support, where it does exist, is often entirely or partly dependent

on charitable grants and donations. Without stable funding and commissioning, access to provision remains patchy, and services fragile.

That being said, the need for psychological support following pregnancy loss and stillbirth is recognised in NICE guidance<sup>10</sup> and there is currently a political focus on improving mental health care. The “Better Births” report, Maternity Transformation Programme and NHS Long Term Plan all highlight plans to improve perinatal mental health care, with funding attached.

Local Maternity Systems (LMS) have been set up to deliver the Better Births vision, including delivering safer maternity care and ensuring that maternity care is personalised and supports women’s needs and choices. LMS are also working towards all women having a Personalised Care and Support Plan by 2021. NHS England/Improvement has also commissioned the University of Liverpool<sup>11</sup> and partners to develop and share good practice on supporting mental health in maternity and neonatal settings to inform local services. This project, will consider care for those who have suffered

a loss within these settings, and therefore could help to set out clear referral processes.

The NHS Long Term Plan also commits to increasing access to evidence-based care for women experiencing moderate/complex–severe mental health problems. New maternity outreach clinics will seek to integrate maternity, reproductive health and psychological therapy for women experiencing mental health difficulties directly arising from, or triggered by the maternity experience. There is also a commitment to expanding access to evidence-based psychological therapies within specialist perinatal mental health services, and offering partners of women accessing these services and maternity outreach clinics evidence-based assessment for their mental health, and signposting to support as required. We are committed to working alongside, Government, the NHS and commissioners to ensure that bereaved parents needs are considered and addressed within these developments.

10. Antenatal and Postnatal Mental Health Guidance - National Clinical Guideline Number CG192 and Ectopic pregnancy and miscarriage: diagnosis and initial management NICE Guideline number NG126

11. Research led by Pauline Slade at the Institute of Human and Life Sciences, University of Liverpool

## What we are calling for

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- The Governments must:**
- 1. undertake a review of current provision including an evaluation of models of best practice, involving parents and professionals
- 2. develop quality standards and national guidance to support those planning, funding and delivering specialist psychological support services for bereaved parents
- 3. ensure that relevant professionals across health services receive mandatory training in the identification of psychiatric illness in parents who have experienced pregnancy and baby loss
- 4. provide guidance to support local services to effectively assess the psychological support needs of bereaved parents, and develop referral pathways to meet those needs

- Commissioners must:**
- 5. allocate sufficient resources for the provision of specialist psychological support for bereaved families based on an assessment of their needs
- 6. ensure that high quality, specialist services are in place for bereaved parents when they need them
- 7. incentivise local services to show how they are meeting the specific needs of this small, but vulnerable group through their inclusion in local data sets and performance measures
- 8. provide clear referral pathways to high quality, effective and evidence-based specialist psychological support





## How MPs can help

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writing to Nadine Dorries, Parliamentary Under Secretary of State for Health asking her to make this a priority



contacting their local CCG and NHS Trust to find out how this support is offered in their area



Please forward any responses received to [babyloss@sands.org.uk](mailto:babyloss@sands.org.uk)

## More information

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Download the

**Out of Sight, Out of Mind: Parents falling through the gaps in mental health care report**

[www.babyloss-awareness.org](http://www.babyloss-awareness.org)

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**#BLAWOutOfSight**

 **Baby Loss  
Awareness Week**  
9-15 October  
[babyloss-awareness.org](http://babyloss-awareness.org)