

OUT OF SIGHT, OUT OF MIND

Bereaved parents falling through the
gaps in mental health care in Northern Ireland

A briefing by
the Baby Loss Awareness Alliance



#BLAWOutOfSight

2. Introduction

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 ¹

1 IN 80

one in eighty are ectopic ² and

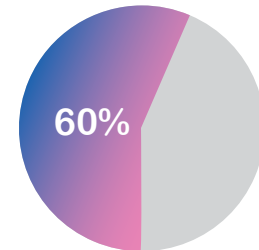
**15 BABIES
A DAY**

are stillborn or die shortly after birth every day in the UK. ³

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 ⁴ 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 ⁴, but were unable to access it on the NHS, 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. ⁵

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) ⁶ “

There is some emerging good practice in England, and with the current focus on improving mental health, and in particular perinatal mental health⁷, 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

2. Ectopic Pregnancy Trust – www.ectopic.org.uk

3. Sands - 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

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 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 the NHS in Northern Ireland to adopt a core set of minimum standards for bereavement care⁸ for parents who have experienced pregnancy or baby loss, to ensure that all parents who need it get the best possible bereavement care. Since then, a review of the current bereavement pathway in Northern Ireland has begun.

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

The current picture



**No
Specialist
support**

In Northern Ireland, in 2018 an NSPCC report highlighted challenges for healthcare professionals in responding to perinatal mental illness. Since then support for new mothers at risk of mental illness has been announced, including funding to train healthcare professionals. We believe the needs of bereaved parents who develop a psychiatric illness must also be taken in to account when planning these services.

None of the Health and Social Care Trusts in Northern Ireland told us that they currently commission a specialist psychological support service, accessible to both parents, who have experienced pregnancy or baby loss. There

is sign-posting to voluntary organisations, however most of these do not offer the kind of psychological support needed by those experiencing a psychiatric illness. They also told us that bereaved parents could be referred to more general psychological support, but parents told us, these services lack the specialist skills and knowledge to support them. Partners' needs are also often overlooked.

This is clearly unfair and inequitable, and the new focus on perinatal mental health services is the perfect opportunity to address this.

What we are calling for

- National recommendations:**
- 1. a review of current provision including an evaluation of models of best practice, involving parents and professionals
- 2. quality standards and national guidance to support those planning, funding and delivery of 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. 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 MLAs and MPs can help



MLAs and MPs can support our work to ensure that all parents who experience pregnancy and baby loss, and need specialist psychological support can access it, by contacting their local Health and Social Care Trust to find out how this support is offered in their area.



Please forward any responses received to babyloss@sands.org.uk

More information

Download the

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

www.babyloss-awareness.org

Telephone: 0203 897 3212

Email: babyloss@sands.org.uk

www.babyloss-awareness.org

#BLAWOutOfSight

 **Baby Loss
Awareness Week**
9-15 October
babyloss-awareness.org