

OUT OF SIGHT, OUT OF MIND

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

A briefing by
the Baby Loss Awareness Alliance



#BLAWOutOfSight

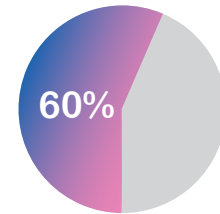
Introduction

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. 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 NHS¹, and in Wales none of the Health Boards who responded to our request for information, could tell us they commission talking therapies specifically for this group, that both parents can access².



“ 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)³ ”

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. We are committed to working alongside decision makers to develop the evidence and solutions to tackle this.

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

2. 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

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

Progress since Baby Loss Awareness Week 2018

During Baby Loss Awareness Week 2018 we called for the Welsh Government and NHS Wales to take definitive action to improve the care that parents receive after pregnancy or baby loss. Specifically we asked them to adopt a core set of minimum standards for bereavement care for parents who have experienced pregnancy or baby loss.

Since then, shortcomings in access to bereavement care in Wales have been noted by the Minister for Health and Social Services. The Independent Review of Maternity Services at Cwm Taf University Health Board highlighted the significant failings in the quality of bereavement care and explicitly recommended that consideration be given to **“implementing the National Bereavement Care Pathway”**⁴.

The Welsh Government announced the formation of a Bereavement Support Working Group in January 2019, to consider evidence and assess what could be done to improve the support provided to families affected by pregnancy and baby loss. Following an initial meeting, we are awaiting the publication of a report from the End of Life Care Board which will review the provision of bereavement services across Wales. In the meantime, the quality of care for parents experiencing pregnancy or baby loss in Wales remains patchy and challenging to access.

4. <https://gov.wales/review-maternity-services-former-cwm-taf-university-health-board-report>

The current picture

PTSD



NO HEALTH BOARDS RESPONDED

There have been reports in the media of parents suffering severe mental health difficulties, such as PTSD following bereavement, being left to arrange their own care, with little support.⁵

No Health Boards in Wales who responded to our request for information were able to tell us that they commission a specialist psychological support service which is accessible to both parents who have experienced pregnancy and baby loss.

Members of the Baby Loss Awareness Alliance are working closely with individual Boards, and the Independent Maternity Services Oversight Panel – Cwm Taf Morgannwg University Health Board, to help push for local improvements. The End of Life Care Board review and the Bereavement Support Working Group are expected to identify areas needing extra resource by the end of the year. This presents an excellent opportunity to outline the necessary improvements to both bereavement care, and specialist psychological support for parents who experience pregnancy or baby loss in Wales.

5. <https://www.itv.com/news/wales/2019-09-12/cardiff-mother-calls-for-more-accessible-mental-health-services/>

What we are calling for

- 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 AMs and MPs can help

AMs 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:

- writing to Vaughan Gething, Minister for Health and Social Services asking him to make this a priority
- contacting their local Health Board 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

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