

Cynulliad Cenedlaethol Cymru | National Assembly for Wales

Y Pwyllgor Plant, Pobl Ifanc ac Addysg | Children, Young People and Education Committee

Techyd Meddwl Amenedigol - Gwaith dilynol | Perinatal Mental Health - Follow-up

PMH(2) 06

Ymateb gan: Bliss

Response from: Bliss

### About Bliss

Bliss is the UK charity that champions the right of every baby born premature or sick to receive the best care. We achieve this by empowering families, influencing policy and practice, and enabling life-changing research.

### Summary

- Bliss is disappointed with the Welsh Government's progress report, which does not sufficiently address to what extent neonatal units are compliant with national standards for psychological support provision on neonatal units, or what steps the Welsh Government is taking to ensure compliance.
- Bliss also notes that no progress update was provided six months after publication of the Perinatal Mental Health report, and the reason for not meeting this deadline have not been explained.
- Further clarification is required as to progress that has been made to improve access to psychological support *specifically* on neonatal units.
- Despite the welcome publication of the *All Wales Neonatal Standards* (3<sup>rd</sup> Edition), the Welsh Government and NHS Wales needs to provide further clarification as to how Health Boards and neonatal units will be supported to resource and implement them.

### Introduction

In 2016 over 2,800 babies were born in Wales needing specialist support from a neonatal unit. For parents of babies born premature or sick, the experience can be deeply

traumatic. Rather than taking their baby home shortly after birth, their baby is admitted to a specialist hospital unit to receive care that ensures they have the best possible chance of survival and quality of life. How long a baby will stay in neonatal care can vary, from days to weeks or months.

For most parents, their baby's admission to neonatal care will be unexpected. The time they are on the unit is often uncertain and filled with stress and anxiety so it is unsurprising that parents whose baby has a neonatal experience are more likely to experience poor mental health than the general population.<sup>1</sup>

### **Bliss involvement in the Perinatal Mental Health Inquiry**

Bliss was delighted to provide evidence to the Children, Young People and Education Committee in May 2017, and were pleased to see families with a neonatal experience recognised in recommendation 21:

*That the Welsh Government **outline within six months** of this report's publication how it expects the **lack of psychological support** for neonatal and bereaved parents **to be addressed** and standards to be met, and what steps it will take if compliance with the standards is not achieved. The **third edition of the neonatal standards should be published as a matter of priority.***

In January 2018, Bliss submitted further information to the Children, Young People and Education Committee welcoming the Welsh Government's commitment to meet the recommendations, but urged the Welsh Government to consider how specific support for families affected by neonatal care could be incorporated more widely into the implementation of other recommendations, so parents with this experience could be appropriately supported in the community as well as directly on the neonatal unit.

### **Addressing psychological support for parents of babies in neonatal care and bereaved parents**

Bliss is extremely disappointed with the Welsh Government's progress report regarding psychological support for parents of babies in neonatal care and bereaved parents. In particular, we are concerned that the Government failed to outline within the required six months how the lack of psychological support in neonatal services would be addressed, and that no service improvements have yet been implemented to ensure compliance with standards.

### Leads for maternity bereavement support

While we welcome the fact that there are maternity bereavement leads in every Health Board and partnership working with SANDs; the Welsh Government's update makes no mention of the specific role that these leads have in relation to improving support for families of babies who die in neonatal settings, and whether any neonatal staff have been able to access and additional bereavement training provided by these roles.

Additionally, while it may be appropriate in some circumstances for maternity bereavement leads to have a remit in relation to bereaved care provision neonatal settings, the Welsh Government's response does not set out any developments in the provision of psychological support for parents who have a baby in neonatal care.

Parents with a neonatal experience will have their own unique journey with a sick or premature baby which can have a profound, long-term impact. In a recent parent survey:

- 62 per cent of respondents told Bliss that they felt they didn't have access to support when they needed it on the neonatal unit
- 80 per cent told Bliss that their mental health became worse after their neonatal experience
- Only 13 per cent said they received support from a mental health professional.<sup>ii</sup>

Bliss highlighted in both oral and written evidence to the committee that neonatal services in Wales are severely lacking the resources they require to support families. Our 2016 report revealed:

- Only 5 out of 11 neonatal units in Wales were able to offer parents access to psychological support of any kind, either on the unit or via referral.
- 0 out of 3 NICUs had a dedicated mental health work available to parents without delay.
- 2 out of 3 NICUS were unable to offer parents any trained mental health support at all, even via referral.
- Parents of the most critically ill babies are often left without any emotional support or psychological help.<sup>iii</sup>

More than two years on, there has been no change to the level of psychological support provided by neonatal intensive care units in Wales, even though the revised standards make it clear every unit should have sufficient access for parents, siblings and staff in place.<sup>iv</sup>

This means thousands of families - including hundreds with critically ill babies or babies who have died on the neonatal unit - have been unable to access suitable support during this time.

The Welsh Government's response also highlights the work to be undertaken by the End of Life Care Board to scope the provision of bereavement services across Wales, however the *Palliative and End of Life Care Delivery Plan* made no mention of end of life care of babies, or neonatal services. Indeed, it appears the Board's focus for children and young people is focused on children living with life-limiting conditions and those receiving palliative care - with neonates specifically excluded. <sup>v</sup>

Since the Committee's report was published, a National Bereavement Care Pathway for Pregnancy and Baby Loss (NBCP) has been developed by a core group of charities led by Sands and with support from Bliss, health professionals and bereaved parents with funding from the Department for Health and Social Care and the Scottish Government. In Baby Loss Awareness Week in October 2018 the NBCP launched a core set of bereavement standards for all settings in which pregnancy and baby loss may occur and made all of its resources freely available.

**Recommendation:** for the Welsh Government to clarify whether neonatal units receive input from the leads for maternity bereavement support and whether there are plans to introduce a similar role for neonatal units.

**Recommendation:** for the Welsh Government and NHS Wales to endorse the NBCP bereavement care standards across all pregnancy and baby loss pathways and in all settings where baby loss may occur, and develop a comprehensive and inclusive approach setting out how they will implement these standards.

**Recommendation:** for the Welsh Government to clearly set out what steps it will take to ensure compliance with neonatal standards in terms of providing access to psychological support for parents with a baby in neonatal care.

**Recommendation:** for the Welsh Government to clarify to what extent the scoping work undertaken by the End of Life Care Board alongside Marie Curie will include a review of bereavement services available in neonatal units.

#### Reporting and reviewing adverse neonatal outcomes

The Welsh Government's response highlights how the 'robust' processes in place for reviewing and learning from neonatal deaths and other adverse incidents through the use of the Perinatal Mortality Review Tool and regular reporting to

MBRRACE-UK. While this is welcome and participation in reviews is key to learning lessons, improving quality of care and ultimately improving babies outcomes, they are not a mechanism for providing psychological support for parents.

**Recommendation:** for the Welsh Government to clarify how neonatal unit participation in these review programmes is supporting them to improve access for parents to psychological support on neonatal units.

### **Third edition of the neonatal standards**

The Minister asserts in the one year update that the 3<sup>rd</sup> edition of the *All Wales Neonatal Standards* have been approved and introduced, and that there is an expectation for Health Boards to work together with the support of WHSCC and the neonatal network to ensure neonatal services operate in line with professional standards.

However, there is no commitment from the Minister for how the Government is going to support Health Boards and neonatal units to implement the standards to ensure all units have 'enough psychologists, counsellors and other mental health workers available to allow parents, sibling and staff access to psychological support' in line with the *All Wales Neonatal Standards*.

In a competitive funding environment, it can be difficult for units to secure the required funding to establish psychological support at unit level. In order for the *All Wales Standards* to be implemented fully, Bliss would urge the Welsh Government and Welsh Health Specialist Service Committee to consider what support and resources Health Boards and the neonatal network require in order to realistically achieve implementation of these critical standards.

Currently the Minister's assurances in the Welsh Government's response that they 'expect Health Boards to ensure...their neonatal service plans are sufficiently robust to achieve the *All Wales Neonatal Standards*' is inadequate. Without a resource commitment to aide implementation it is highly unlikely the standards will be met by all neonatal units in Wales.

**Recommendation:** For the Welsh Government and Welsh Health Specialist Service Committee to set out what steps it will take, and resource it will provide, to support neonatal units to achieve compliance with *All Wales Neonatal Standards* (3<sup>rd</sup> Edition)

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<sup>i</sup> Vigod, S.N., Villegas, L., Dennis, C.L., Ross, L.E (2010) Prevalence and risk factors for postpartum depression among women with preterm and low-birth weight infants: a systematic review, *BJOG*, 117(5), pp.540-50

<sup>ii</sup> Bliss (2018) Parental mental health: a Bliss survey on the neonatal unit's impact

<sup>iii</sup> Bliss (2016) Bliss baby report 2016: time for change

<sup>iv</sup> Welsh National Health Service (2017) All Wales Neonatal Standards 3<sup>rd</sup> Edition

<sup>v</sup> Welsh National Health Service and Welsh Government (2017) Palliative and End of Life Care Delivery Plan accessed online at: <https://gov.wales/docs/dhss/publications/170327end-of-lifeen.pdf> p.6