



Neonatal Services for the Future: A vision for Wales

Bliss
for babies born
premature or sick

About Bliss

Our vision is that every baby born premature or sick in Wales has the best chance of survival and quality of life. Bliss champions the right of every baby born premature or sick to excellent neonatal care, experience and outcomes. We achieve this by improving care, giving voice to babies and supporting parents to be partners in care.

Across our 2025-2029 strategy period, we will be prioritising equity for all neonatal babies and families:

Equity of care

every baby born premature or sick benefits from Family Integrated Care which builds a culture of partnership between their parents and the neonatal healthcare team

Equity of voice

every baby born premature or sick has their voice and interests represented by Bliss, to influence improvements in all aspects of their care at local, regional and national levels

Equity of support

every baby born premature or sick has well-supported parents who have the information they need, when they need it, to be partners in their baby's care.

About Neonatal Care

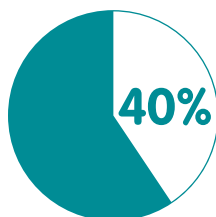
What is neonatal care?

Neonatal care is the type of hospital care that a baby receives if they are born unwell. Babies are admitted to neonatal care shortly after birth, either because they have been born prematurely (before 37 weeks of pregnancy) or at full term but sick. For example, they might have an infection, difficulty breathing or a genetic condition. For parents of these babies, the experience is life changing. Rather than taking their baby or babies home shortly after birth, they are admitted to a specialist hospital unit to receive care which ensures they have the best possible chance of survival and quality of life.

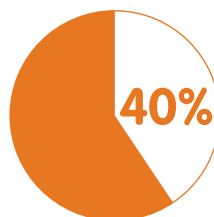
These babies are among the most vulnerable patients cared for by NHS Wales. They may spend days, weeks, and in some cases months in hospital. According to the most recent available data, in 2023, 72 babies sadly died during the neonatal period (the first 28 days of life) in Wales¹. Many of these deaths occurred on the neonatal unit.



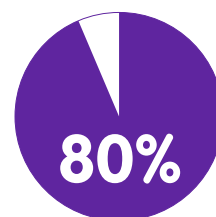
babies born in Wales is admitted to neonatal care (around 3,000 babies per year²)



of babies admitted are premature, 60% are full term but sick



of babies admitted are twins and multiples



of UK parents say their mental health is affected by a neonatal admission³

¹Office for National Statistics (2025) Child and infant mortality (by year of death), England and Wales

²Public Health Wales (2023) Improving Together for Wales: Maternity Neonatal Safety Support Programme Cymru Discovery Phase Report

³Bliss (2018) Supporting better mental health on the neonatal unit – for parents and staff

How is neonatal care delivered?

Neonatal care is delivered at different levels depending on what type of care a baby needs – intensive care, high dependency care or special care. To read about the different types of care provided in the UK please visit [our website](#).

There are nine neonatal units across Wales. Babies are transferred between neonatal units by the Cymru inter-Hospital Acute Neonatal Transport Service (CHANTS), and CHANTS North which is a specialised division of the Welsh Ambulance Service.

The Wales Maternity and Neonatal Network works to improve the safety and quality of services and improve the experiences of families. Their work includes developing and implementing care pathways, and ensuring families are involved in all aspects of the Network's remit.

Families at the centre of care

NHS organisations across the UK strive to deliver neonatal services through a family integrated model of care^{4,5}. This model ensures that parents and the wider family are active partners in their baby's care. Evidence shows that high levels of parental involvement improve short- and long-term outcomes for babies⁶, reduce parental stress scores⁷ and strengthen bonding⁸. Direct, hands-on care by parents has been linked to increased infant weight gain, improved breastfeeding rates, better infant reflexes at term, and stronger gross motor development by age four to five⁹. When parents can stay on the unit, babies face lower risks of mortality and morbidity and often require fewer days of care¹⁰. Additionally, enabling parents to take the lead in routine care can ease staffing pressures, allowing clinical teams to focus on more complex tasks. Providing the right infrastructure to support parental presence in neonatal settings is therefore essential.

Enabling neonatal services to deliver Family Integrated Care (FICare) is critical, and each of the three priorities set out in this manifesto directly contributes to achieving this aim. We can help reduce inequalities in access and outcomes, ensure parents are supported to remain by their baby's side and highlight the need for adequate staffing by embedding families at the heart of neonatal care – to ensure that babies born premature or sick have the best chance of survival and quality of life.

Independent Maternity and Neonatal National Assurance Assessment

An independent national assessment of maternity and neonatal services in Wales was published in February 2026¹¹. While the panel received much positive feedback from new parents and found staff to be strongly committed to delivering high-quality, safe care, the report still highlights several important challenges. These include significant fragmentation in coordination between neonatal units, inconsistent access to neonatal allied health professionals and a lack of infrastructure to support full parental involvement.

Bliss urges the next Welsh Government to accept the report's findings in full, and commit to implementing its recommendations over the coming years.

⁴Welsh Government (2025) Quality statement for maternity and neonatal services

⁵British Association of Perinatal Medicine (2021) Family Integrated Care: A BAPM Framework for Practice

⁶Waddington et al (2021) Family integrated care: Supporting parents as primary caregivers in the neonatal unit

⁷Bergman (2019) Birth practices: Maternal-neonatal separation as a source of toxic stress

⁸Kutahyaliloglu (2022) Effects of family-centered care on bonding: A systematic review

⁹Franck et al (2022) Neonatal outcomes from a quasi-experimental clinical trial of Family Integrated Care versus Family-Centered Care for preterm infants in the US NICUs

¹⁰Lehtonen (2020) Family Rooms in NICUs and Neonatal Outcomes: An International Survey and Linked Cohort Study

¹¹The Welsh Government (2026) The path to safer beginnings in Wales

1. Address inequalities to give every baby the best chance in life

Due to serious inequalities, many babies – including babies from minority ethnic communities and babies born into socio-economically deprived areas – experience disadvantage at birth and are more likely to have poor short- and long-term outcomes.

Bliss recommendations to give every baby born premature or sick equitable care:

- Develop proactive programmes to reduce inequalities in neonatal care, experience and outcomes
- Prioritise the routine, standardised collection of newborn ethnicity and social deprivation data across all Health Boards
- Invest in research to identify and interrogate inequity between babies from different demographic backgrounds.

Background

Latest data shows that Wales has the highest rate of neonatal death in the UK (1.79 per 1,000 live births) compared to the UK average (1.63 per 1,000 live births)¹².

Currently, inequalities exist in the care, experience and outcomes of babies born premature or sick in Wales¹³, and much more needs to be done to reduce unwarranted variation in outcomes. Many of the ways that these inequalities manifest within neonatal care are clearly identifiable – for example, babies from certain ethnic or socio-economic backgrounds have a significantly higher risk of preterm birth¹⁴, and of neonatal mortality¹⁵; and parents from lower socio-economic backgrounds are likely to face financial barriers which prevent them from being partners in their baby's care¹⁶. While it is not well understood how the outcomes of a neonatal stay may vary for babies from different backgrounds, there is emerging evidence that suggests care practices on the neonatal unit could contribute to persistent inequalities in survival¹⁷. Similarly, the extent to which differential experiences of neonatal care may affect some parents' ability to be involved in their babies' care is also not well understood.

In Wales, 7.1 per cent of babies were born in 2022 to mothers of Asian/Asian British or Black/Black British heritage^{18,19}. Although this represents a relatively small proportion of births, it is essential that the experiences and outcomes of these families are not overlooked. This data is not disaggregated by nation, however across the UK, neonatal mortality rates are highest for Asian babies (2.35 per 1,000 live births), then Black babies (2.28 per 1,000 live births) and lastly White babies (1.50 per 1,000 live births)²⁰. Overall, neonatal mortality decreased in 2023 from 2022 for babies of all ethnicities, but deprivation disparities are widening²¹.

¹²MBRRACE-UK (2025) Perinatal mortality surveillance

¹³Welsh Government (2025) Quality Statement Maternity and Neonatal Services

¹⁴House of Lords Preterm Birth Committee (2024) Preterm birth: reducing risks and improving lives

¹⁵MBRRACE-UK (2025) Perinatal mortality surveillance

¹⁶Bliss (2022) Impact of cost-of-living crisis in neonatal care

¹⁷Saberian, Samira et al. (2025) Inequalities in neonatal unit mortality in England and Wales between 2012 and 2022: a retrospective cohort study *The Lancet Child & Adolescent Health*, Volume 9, Issue 12, 857 - 867

¹⁸ONS (2024) Birth characteristics in England and Wales: 2022

¹⁹It is important to note that a baby's ethnicity may not always match that of their mother

²⁰MBRRACE-UK (2025) Perinatal mortality surveillance

²¹MBRRACE-UK (2025) Perinatal mortality surveillance

It is well documented that babies are more likely to die shortly after birth if they are born to mothers already facing inequality or disadvantage. The most recent Welsh Index of Multiple Deprivation found that 28 per cent of all children aged 0 – 4 in Wales lived in income deprivation²². Babies born into poverty are more likely to experience adverse birth outcomes, including low birthweight²³ and prematurity, both of which increase the risk of neonatal mortality²⁴. Disparities in neonatal mortality rates by socio-economic deprivation widened further in 2023. Rates increased for babies born to mothers from the most deprived areas (from 2.38 per 1,000 live births in 2022 to 2.50 in 2023), a rate now more than double that of babies born to mothers in the least deprived areas, where the rate decreased from 1.18 per 1,000 live births in 2022 to 1.03 in 2023²⁵.

Understanding disparities and how to reduce them

The disparities in neonatal outcomes between ethnic groups and the poorer outcomes faced by those in areas of higher deprivation are shocking. Some of these differences are evidently related to the care received antenatally in maternity services, and wider socio-economic issues faced by their family. Research by Bliss found that families on lower incomes typically had lower levels of parental involvement²⁶. We have also highlighted inequalities in the way families from South Asian backgrounds²⁷ and young parents²⁸ access and experience neonatal care.

There is a lack of data about the ways that inequalities drive differences in neonatal outcomes and, crucially, how the inequalities that exist in society play out on the neonatal unit. Some of this work has already begun, for example, research shows that the widespread use of diagnostic tools which rely on changes in skin colour to identify serious illness in newborns put Black, Asian and minority ethnic babies at risk^{29,30}. Therefore, investment must be made in research to identify and interrogate inequity between babies from different demographic backgrounds to drive evidence-informed improvements.

The importance of improving data collection

To effectively address disparities in neonatal outcomes, the new Welsh Government must commit to improving data collection and analysis. There must be a drive to accurately record babies' ethnicities, as mothers and babies do not always share the same ethnicity. This is essential for exploring disparities in outcomes for babies needing neonatal care.

Improving data collection is a foundational step toward evidence-based policymaking. Without robust, disaggregated data for mother and baby, the specific challenges faced by these communities often remain invisible within broader population statistics. It allows for a more granular understanding of how ethnicity and socio-economic status interact to shape outcomes, and it supports the development of culturally competent, inclusive services.

²²Welsh Government (2019) Welsh Index of Multiple Deprivation 2019: deprivation analysis relating to young children

²³Welsh Government (2019) Welsh Index of Multiple Deprivation 2019: deprivation analysis relating to young children

²⁴Thomson et al (2021) Socioeconomic inequalities and adverse pregnancy outcomes in the UK and Republic of Ireland: a systematic review and meta-analysis

²⁵MBRRACE-UK (2025) Perinatal mortality surveillance

²⁶Bliss (2022) Impact of cost-of-living crisis in neonatal care

²⁷Bliss (2022) South Asian Families' Experiences Report

²⁸Bliss (2021) Neonatal care through a young parent lens

²⁹KWISA (2024) Nothing About Us Without Us: Women of African and Caribbean Heritage Community Voices Report

³⁰NHS Race Health Observatory (2023) Review of neonatal assessment and practice in Black, Asian, and minority ethnic newborns

2. Support parents to be at their baby's cot side and involved in care

Neonatal services are configured to ensure babies have the best possible chance of survival and quality of life. Babies need to receive the right level of care, at the right time, for this to be possible. While services always aim to care for babies as close to home as possible, the specialised nature of neonatal care means that sometimes care must be provided unavoidably far from home.

There are a number of barriers to parents' ability to be by their baby's cot side and involved in care. These include a lack of overnight accommodation for parents on the unit and the financial burden associated with a neonatal admission. Most parents must leave their baby's side in hospital overnight, because somewhere to sleep on a neonatal unit is not routinely provided. Parents need practical and financial support to enable them to be with their baby as much as possible.

Bliss recommendations to support parents to be at their baby's cot side and involved in care:

- Develop a small grants programme so that Health Boards can apply for funding immediately to buy new furniture or equipment to improve the neonatal environment and provide parents with the facilities to support them being partners in their baby's care
- Identify the capital investment required to bring all parent accommodation up to a minimum standard on neonatal units over the medium term
- Establish a Neonatal Expenses Fund to help with the high costs to families of being partners in their baby's care.

Accommodation

Providing parents with somewhere to stay – whether that be in on-site private rooms, in family accommodation near the hospital, or on pull out beds at the cot-side – is key to enabling and delivering the benefits of FICare. However, inadequate provision of accommodation across Wales is resulting in parents being unable to be partners in their baby's care on a regular and consistent basis. For some parents, this lack of infrastructure means they are unable to be with their baby every day.

Our research found that:

- Nearly nine in ten babies in Wales cannot have their parents stay in a room overnight on the unit³¹
- 87 per cent of UK parents without access to overnight accommodation say that this stopped them being involved in their baby's care some of the time³²
- Parents describe leaving their baby at night to return home as one of the hardest parts of having a baby in neonatal care
- To many parents, meaningful involvement in their baby's care often means doing night-time feeds and being with their baby during the night - just as they would expect to do at home or on a paediatric unit³³.

³¹Bliss (2024) Families Kept Apart in Wales

³²Bliss survey results from a sample of more than 1900 parents

³³Bliss survey results from a sample of more than 1900 parents

The Welsh Neonatal Service Specification highlights the requirement for services to provide FICare³⁴ and mandates that “facilities and resources should be available to enable parents/carers to be resident with their baby for as long as they want and are able to be. This includes sufficient accommodation on or close to the neonatal unit for families”. Most recently, the Maternity and Neonatal National Assurance Assessment found that while services tried their hardest to use the accommodation they had flexibly, provision was inequitable. This was particularly prominent in neonatal units, impacting FICare delivery, and reliance on charitable funding rather than centralised capital funds was identified as a key issue³⁵.

Neonatal Expenses Fund

Families, particularly those on low incomes, face an unfathomable choice between being fully involved in their baby’s care and getting into debt³⁶. In Scotland, the now Young Patients Family Fund – expanded from an original Neonatal Expenses Fund – is available for parents to pay for transport, parking, meals and overnight accommodation, and we recommend the introduction of a similar scheme in Wales.

This approach is tried and tested. In an evaluation of Scotland’s Neonatal Expenses Fund, parents reported that being able to claim from the fund relieved financial anxieties during a very stressful period and helped them spend more time with their babies in the neonatal unit³⁷.



³⁴NHS Wales (2024) Neonatal Services (Intensive Care, High Dependency and Special Care)

³⁵The Welsh Government (2026) The path to safer beginnings in Wales

³⁶Bliss (2022) Bliss briefing: Impact of cost-of-living crisis in neonatal care

³⁷Scottish Government (2019) Neonatal Expenses Fund year one: evaluation

3. Create a neonatal workforce for the future

Babies need to be cared for by a fully staffed, multidisciplinary team of healthcare professionals to have the best outcomes. However, workforce levels on neonatal units do not currently meet the safe staffing standards set out by national bodies.

Bliss recommendation to ensure the safety and quality of neonatal services:

- Fully implement the Strategic Perinatal Workforce Plan over the next three years to ensure neonatal units have adequate nurse, medical, Allied Health Professional, Psychologist and Pharmacist staffing for their numbers of cots, in line with national standards for numbers and skillset.

Research shows that the safety of neonatal services relies on units meeting nationally mandated minimum staffing numbers. Where there are not enough nurses, doctors and Allied Health Professionals, Psychologists and Pharmacists (AHPPPs), babies are likely to have worse outcomes – including higher mortality rates – than those who are treated in neonatal units that meet both the required staffing numbers and skills mix³⁸.

The recent Maternity and Neonatal National Assurance Assessment found shortages across all staffing groups – including neonatologists, neonatal nursing and allied health professionals³⁹. This aligns with Bliss' own research, conducted in 2024, which found a 62 per cent overall shortfall between the recommended AHPPP staffing levels for neonatal units and the staffing levels currently being provided in Wales⁴⁰; as well as significant variation between service provision in Wales, with the average staffing shortfall being the highest for psychology at 90 per cent (the second highest in the UK) and the lowest being 40 per cent for dietetics⁴¹.

The Assurance Assessment identified several issues fuelling staffing challenges, including a lack of funding to support posts, high sickness rates and unsuccessful recruitment attempts⁴². This aligns with the findings from Bliss' own research which found significant challenges in recruiting and retaining AHPPP staff due to funding, resource and support constraints⁴³, and echo the findings of the Maternity Neonatal Safety Support Programme (MatNeoSSP) which found teams strained by gaps and ad hoc cover, which impacts on wellbeing, education, training, research and other services⁴⁴. These pressures not only compromise care quality but also contribute to staff burnout and turnover. Investment into quality and training roles is therefore essential for retaining staff in neonatal units, especially given the demands of the job and safety issues caused by understaffing.

³⁸Watson et al (2016) The effects of a one-to-one nurse-to-patient ratio on the mortality rate in neonatal intensive care: a retrospective, longitudinal, population-based study

³⁹The Welsh Government (2026) The path to safer beginnings in Wales

⁴⁰Bliss (2025) Filling the gaps: A spotlight on Allied Health Professional, Psychological and Pharmacy Roles in Neonatal Care

⁴¹Bliss (2025) Filling the gaps: A spotlight on Allied Health Professional, Psychological and Pharmacy Roles in Neonatal Care

⁴²The Welsh Government (2026) The path to safer beginnings in Wales

⁴³Bliss (2025) Filling the gaps: A spotlight on Allied Health Professional, Psychological and Pharmacy roles in neonatal care

⁴⁴Public Health Wales (2023) Improving Together for Wales: Maternity Neonatal Safety Support Programme Cymru Discovery Phase Report

Service redesign to give the best care to the smallest and sickest babies

We know that receiving the right level of care in the right unit is essential for babies to have the best short- and long-term outcomes, including the best chance of survival for the smallest and sickest babies⁴⁵. It was therefore concerning to see findings in the Independent Maternity and Neonatal National Assurance Assessment highlight fragmentation in coordination between neonatal units, particularly in South Wales where configuration of neonatal units is impacting the care and experience of babies and families⁴⁶.

Bliss strongly supports the recommendation that the Joint Commissioning Committee make urgent progress in planning a neonatal service model to improve care now and into the future, meaning that more extremely premature and extremely sick babies will survive and survive well. We urge the next Welsh Government to prioritise this recommendation to ensure that required service redesign happens.

Bliss has received funding from the Welsh Government until the end of March 2027 for a programme of work. This programme covers:

- **Supporting all neonatal units in Wales to work towards achieving Bronze level Bliss Baby Charter Accreditation**
- **Improving access to Bliss' information and support for all neonatal families in Wales**
- **Piloting a new digital neonatal parent support service**
- **Training for healthcare professionals**
- **Publication of a report into neonatal inequalities in Wales.**

⁴⁵BAPM (2021) Optimal Arrangements for Neonatal Intensive Care Units in the UK including guidance on their Medical Staffing

⁴⁶The Welsh Government (2026) The path to safer beginnings in Wales



Join the family

If your baby is on a neonatal unit because they were born premature or sick, you're not alone. Find practical information, emotional support and a community of families with a neonatal experience at bliss.org.uk

Join the family, search Blisscharity on



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