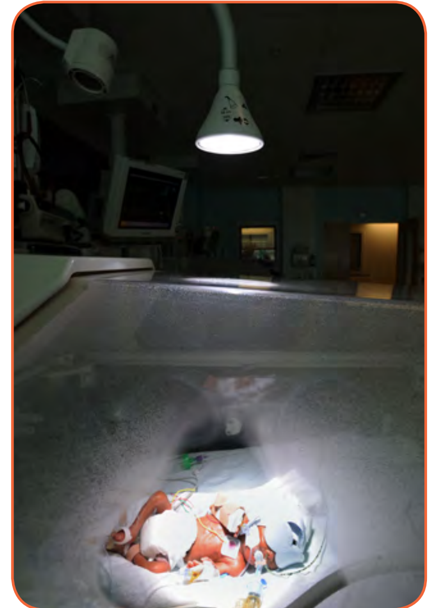
Every Baby Matters



Introduction

Every week in Northern Ireland two babies are stillborn and a further two babies will die shortly after birth.

In the same period around 35 newborn babies will be admitted to neonatal care in Northern Ireland. Of these, nine will require life-saving intensive care.

Behind these statistics are precious babies and families. The support they receive at these times is critical.

"You never forget the loss of your baby; you just get better at coping with the grief. There is never a day when I do not think about Fred and wish he was here."

Bereaved parent

"It was such an emotional and terrifying time for us, it is almost unexplainable. We were so scared the twins were going to die, it is still very difficult to deal with three years on."

Parent of premature twins

Rates of stillbirth throughout the UK are at unacceptable levels. Too often the death of a baby before or soon after birth is at best ignored, at worst considered 'just one of those things'. One baby in every 200 is stillborn – that is ten times the number of cot deaths. One in ten babies born in Northern Ireland is admitted to neonatal care. Meanwhile premature births are still rising and more and more families continue to require more specialised support.

Bliss, Sands and TinyLife have more than 80 years of combined experience supporting families whose babies are born premature or sick, or who have died. We have worked collaboratively with researchers, health professionals, families and policy makers to improve services for special care babies, advance strategies for the prevention of stillbirth and neonatal death, and ensure better family support and bereavement care.

We want the Northern Ireland Executive to show that Every Baby Matters by

- **prioritising perinatal mortality as a major public health issue**
- **improving care for babies born premature or sick, and**
- **supporting the delivery of front line services to families.**

Sands
Stillbirth & neonatal death charity

Tiny Life
The premature baby charity for Northern Ireland

Bliss
for babies born too soon, too small, too sick

Preventing babies dying or being born too soon

Northern Ireland's birth rate has risen dramatically in the past decade, up by 20 per cent since 2002[i]. At the same time, the profile of the pregnant population is changing with a rise in some of the factors known to increase the risk of stillbirth and premature birth.

Encouragingly, Northern Ireland's track record on preventing babies from dying is better than the rest of the UK. In 2007 Northern Ireland's perinatal death rate – which includes stillbirths and deaths in the first seven days after birth - was 4.1 per 1,000 total births: significantly lower than 5.4 for England and Wales and 5.9 for Scotland[ii]. But there are worrying signs that the falling mortality in the early 2000s could now be reversing as the stillbirth rate in recent years has increased[iii].

These deaths are not considered a public health priority. Yet the stillbirth risk is already ten times that of cot death, and even higher when known risk factors are taken into account including obesity, smoking, social deprivation, teenage pregnancies and older mothers - all key issues facing the health of the public in Northern Ireland. The same risk factors are also attributable to many premature births.

High quality prenatal and antenatal advice and care must be available to all women, and targeted at the most vulnerable women whose risk of having a stillborn or premature baby is highest.

"My husband and I went off to hospital looking forward to meeting our new baby. Nothing could have prepared me for the horror of being told that she was dead."
Bereaved parent

Understanding how to prevent stillbirths

Not all stillbirths are unavoidable and inevitable. Evidence already shows that a significant number could be prevented with better understanding about why pregnancies go wrong, and with better care.

Over half of all stillbirths are 'unexplained', leaving parents asking why their apparently perfectly healthy baby has died. Research is urgently needed to understand what is causing these baby deaths.

While the majority of unexplained stillbirths happen in pregnancies that were considered problem free and low-risk, it is well recognised that many of these babies do exhibit risk factors such as poor growth of the baby in the womb. Many unexplained stillbirths occur at gestations when the baby might safely be delivered, if those pregnancies could be reliably identified. But in too many cases the failure of these babies to thrive is not picked up until it is too late. New interventions and new ways of monitoring babies in the womb need to be developed and tested.

"When we do detect a sick baby in the womb after 26 weeks we rarely lose it. Doctors and midwives should work together to ensure good medical care for all pregnancies, so that we can improve our detection of the high risk baby being carried by the low risk mum."
Professor Jim Dornan, Head of Fetal Medicine Department, Queen's University, Belfast.

Services under pressure

Better care for pregnant women and their babies

All pregnant women need care from midwives and doctors who have the time, skills and tools to assess the pregnancy properly at each visit.

Northern Ireland has had a culture of antenatal care and labour ward practice that emphasises close surveillance of all pregnancies, including low-risk mothers, and there are traditionally good working relationships between midwives and doctors. But the relatively lower perinatal death rates must not lead to complacency. The reorganisation of the country's maternity services, against the backdrop of recession, is putting pressure on services. There is concern that the closure of wards and pressures on staff could reduce the quality and safety of antenatal care.

Over half of Northern Ireland's midwives are due to retire in the next ten years, leaving a gap of experience within the service; others are leaving before retirement age, exhausted by the pressures of the job. While the number of student places has increased, there are insufficient graduates to fill the vacancies, and a growing imbalance in the level of experience of staff on the wards. Initiatives are needed to encourage midwives to stay in the profession, and to accelerate the number of new midwives coming through training.

"Northern Ireland's low stillbirth and neonatal death rate will not be maintained if cutbacks continue in frontline maternity services."
Alyson Hunter, Consultant Obstetrician, Royal Jubilee Maternity Hospital, Belfast

Better care for babies born too soon or too sick

Around 2,000 babies were admitted to neonatal care in Northern Ireland in 2007[iv].

Over the last decade there has been a huge increase in the number of babies receiving neonatal care in Northern Ireland, with 43 per cent more babies receiving intensive and high dependency care in 2006 than in 2001/2[v]. This increase is due to more and more babies surviving at early gestations and after grave illness thanks to significant advances in treatments for babies, improvements in the care mothers receive throughout their pregnancy, as well as the rising birth rate and socio-economic factors discussed above. Admissions are likely to remain high as further treatments become available in the future

We wholeheartedly welcome the fact that more babies born too soon and too sick are surviving, but the huge increase in demand for neonatal care has inevitably put the service under strain. Following a review of services for premature and sick babies in Northern Ireland, commissioned by the Chief Medical Officer in 2005, £800,000 was allocated to improving paediatric and neonatal intensive care in 2007/8. This additional investment funded an increase in staffed cots and recommended setting up a dedicated neonatal transport service to provide safe transfers of babies and pregnant women in need of special care. Some funding has recently been provided to set up this transport service, but it is not enough to provide a round the clock service, as is the standard in Scotland and England.

Although the number of specialist neonatal nurses in Northern Ireland has marginally increased in recent years, research by Bliss from 2008 showed that another 70 nurses are needed to provide the standard of care required[vi], as set out by the British Association of Perinatal Medicine (BAPM).

In addition, admissions to neonatal care fluctuate, and issues remain about the ability of services to cope during peak periods. Bliss' research also showed that the average occupancy levels in five out of the seven neonatal units in Northern Ireland exceeded the recommended 70 per cent, and in several units frequently exceeded 90 or even 100 per cent. It also revealed that nearly two fifths of babies being transferred from one unit to another was due to a lack of capacity rather than for medical reasons.

It is agreed best practice that babies born at less than 26 weeks are cared for at the specialist centre at the Royal Maternity Hospital in Belfast. However research published last year shows that, in 2006 (the most recent figures available) more than two fifths of babies born at less than 26 weeks were initially cared for outside of this specialist centre. In 2001/2 this was less than one in four[vii]. The likely cause of this is a lack of intensive care cots in the specialist centre.

It is not acceptable that these extremely vulnerable babies are not getting access to the care they need. Neonatal services in Northern Ireland must be set up to meet the needs of our most vulnerable babies, whenever they are born.

"Our twin boys were separated for six days due to a lack of cots at our nearest unit. The staff at both hospitals were helpful and considerate and the care our boys received was amazing but it broke our hearts that they were separated and it was a very difficult and traumatic time."
Parent of premature triplets

Better post mortem services

Post mortems can provide important information for families about the cause of their baby's death, and are also critical in the search to identify why these babies are dying. Uptake of post mortems in Northern Ireland is higher than elsewhere in the UK. Perinatal post mortems are performed by consultants within 24 hours and initial feedback has been rapid – all of which encourages parents to give consent

But the Belfast team that provides the perinatal pathology service to the whole of Northern Ireland is now under severe strain, with consequences for the level of service being offered.

"Sadly, paediatric pathology in Northern Ireland is at present severely compromised due to a lack of funding and excessive workloads. We have had to limit the placental examinations to those cases in which the baby has died, the turnaround time for final post mortem reports is unacceptably long and we are unable to offer the training and support we would like to maternity units across the region."
Claire Thornton, Paediatric Pathologist, Royal Victoria Hospital, Belfast

For bereaved parents, long delays in waiting for post mortem results are extremely traumatic. If the standards of service are not maintained fewer parents are likely to make the already difficult decision to agree to a post mortem in the future. If the post mortem rate is to improve, or even to be sustained, the perinatal pathology service must be better resourced.

Support for families

Caring for bereaved families

The death of a baby, whether before their birth or in the days immediately afterwards, is no less a death than the death of any other child. A child who dies early in their life is no less loved and cherished. It is hard to overstate the levels of trauma and devastation bereaved families experience.

Parents whose baby has died need support and a safe place to be with their baby in the all-too-short time that they have. All maternity and neonatal units should have appropriate facilities, and staff with training and experience to offer sensitive support. We support the bereavement charity Life After Loss' recent call for a bereavement midwife to be present in every maternity unit. At the very least bereavement training should be mandatory for all midwives, neonatal nurses, and obstetricians.

While it may take some time to get a fully trained bereavement midwife into each unit, Northern Ireland's trusts could provide vital support for parents by replicating the model of the 'Forget me not Group', now established at the Ulster Hospital. This multi-disciplinary liaison group, which includes parents, aims to improve services for families, whether they have experienced a miscarriage, stillbirth or neonatal death. The group was recognised with joint first award from the National Childbirth Trust (NCT) for "good practice in supporting parents in the early months".

Support for families of babies in neonatal care

While nothing can equal the grief of losing a baby, having a baby admitted for specialist care can also be an extremely stressful and emotionally turbulent time for families. While most parents can expect to meet their baby immediately after birth, parents of sick and premature babies often have to wait hours and sometimes days to even see their baby for the first time.

Having a baby transferred to a hospital far away from home can add to the stress and worry that is inevitable when a baby is admitted to neonatal care. Not only that, but long distance transfers can also pose enormous practical and financial problems for families. Research commissioned by Bliss to assess the social impact of transfers on families has just been published. The study surveyed mothers who were transferred just before giving birth. Over half reported feeling socially isolated as a result of being transferred; a fifth reported that their transfer had caused family difficulties; three out of ten reported financial problems as a result of the transfer; and 15 per cent reported that families had difficulties in finding local accommodation[viii].

Transfers are a necessary part of neonatal care in Northern Ireland but the impact that they can have on family life is clear. There is a pressing need to ensure that services are better planned to meet the needs of families, and minimise the occurrence of such avoidable distress and disruption.

"I had to be transferred with my premature triplets to Scotland due to a lack of cot space in Northern Ireland. This was a very traumatic time for us and we feel that families should not have to go through this."
Parent of premature triplets

There is also a need to consider the longer term impact of having a premature or sick baby on family life and parent-infant interactions. Previous research has indicated the consequences of preterm birth are a concern of the whole family. Difficulties regarding isolation and lack of support, marital problems and behavioural symptoms in siblings have been reported widely in national and international research[ix].

Children who were born premature also tend to have more readmissions to hospital, creating further parental stress and possible long term effects on the family. Parents throughout Northern Ireland have voiced the need for consistent long-term support provision in terms of practical, emotional, social and educational needs.

These parents are more likely to suffer from depression and anxiety at the time of the hospital discharge of their baby[x]. This adds to the isolation and emotional trauma normally associated with having a premature birth, thus illustrating the importance and potential preventative impact of support interventions.

Parents of premature and ill babies also experience feelings of guilt, hopelessness, fear, shock and sadness. It is very distressing to watch your baby, or indeed babies, fight for life, feeling completely powerless to help. Dads can easily become overlooked because the focus tends to be on the mother and the baby.

While these outcomes for families of preterm babies have been widely known in recent decades, statutory services have not responded to these needs. More recently, commissioners have been reluctant to recognise the value of support services, which the voluntary sector has been willing and able to provide, such as those provided by TinyLife's 'Hospital to Home' service.

Recommendations

Care for babies and their families in Northern Ireland could be a beacon of best practice for the rest of the UK. We believe now is the time to focus on maintaining standards and investing in those services that are falling short. The lives of babies must not be put at risk by compromising the quality of vital services.

We recommend that

- **public health initiatives must make perinatal mortality reduction a priority alongside infant mortality**
- **continuity of care, delivered by well-trained health professionals who have the skills to pick up on individualised risk, is essential to maintaining standards of antenatal care**
- **neonatal care must be provided in complete compliance with BAPM standards, and properly resourced to meet growing demand and peaks in activity**
- **neonatal transport services should be properly resourced to allow safe and timely transfer of babies among units around the clock**
- **specialist support should be available to all parents with a baby or babies in neonatal units throughout Northern Ireland**
- **planning of neonatal services must take into account the impact of transfers on families, including access to accommodation close to the unit where their baby is being cared for and financial support for those who need it**
- **Northern Ireland needs an additional pathologist and associated support staff in order to meet a minimum standard of service**
- **research is urgently needed to understand what is causing so many unexplained stillbirths.**

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