

## **Babies born at the limits of viability: How management decisions impact on parents and the NHS.**

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**Scope:**

While improvements in neonatal care have significantly improved the survival of babies born prematurely, the outcomes at the limits of viability (less than 24 weeks gestational age) remain extremely poor. Despite the rarity of births at this early gestation, there is wide variation in clinicians' practice in the recording of these babies as being born alive or not. This article explores the ways that different approaches to the management of babies delivered at the limits of viability can impact on both parents' experiences and the NHS.

**Keypoints:**

- Wide variation exists in clinicians' practice in whether babies born at the limits of viability are recorded as live born.
- This has often unrecognised consequences in terms of inequalities in parents' access to maternity and paternity leave and financial support, and biased estimates of mortality rates for health organisations.
- Reflection on practice may lead to improved outcomes for parents.
- Improved national reporting of fetal losses before 24 weeks will allow reliable exploration of variations in quality of care provision between health organisations.

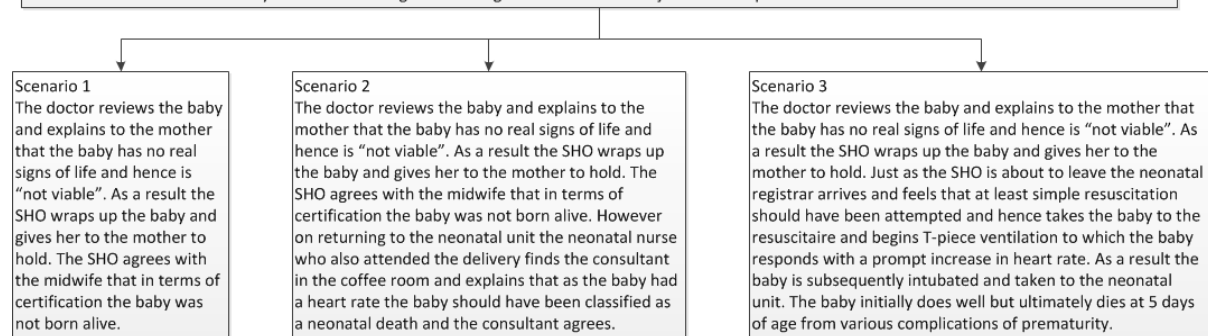
**Keywords:** limit of viability; fetal loss

## Managing babies born at the limits of viability

The birth of a baby at the limit of viability (which for the purposes of this article includes any baby born less than 24 weeks of gestation) with little or no warning is a situation familiar to most clinicians involved in neonatal care. Box 1 describes a typical clinical situation relating to a baby born at this gestation and three scenarios of how it might be dealt with in three different units.

### Box 1: A typical clinical scenario of a baby born at 23 weeks gestational age and possible outcomes

At 2200 the neonatal SHO covering labour ward receives a phone call to let her know that a lady has been admitted at 22 weeks and 6 days with bleeding from the vagina and with some contractions. The obstetric team have concluded that at this gestation, should the baby deliver, the outlook is extremely poor and hence have spoken to the mother and agreed that they will simply await events and not monitor the labour or plan to intervene. At 0200 the same doctor is bleeped urgently to labour ward because the baby is delivering. On arrival the baby, a little girl now 23 weeks exactly, appears compatible with that gestation and weighs 600g. The midwife reports that the baby has not cried or shown signs of respiration but was moving when first born and did have a slow heart rate of around 60. The baby is now not moving or breathing and the heart rate is just 40 beats per minute.



In all three scenarios outlined in Box 1 the clinicians involved acted in a way that they felt was in the best interests of the family. It seems clear the baby was not going to survive but the circumstances of the baby's death were quite different following the registrar's intervention in scenario 3 and the wider implications of the child's death are different in all three scenarios. It is relatively common for neonatal unit teams to review clinical decision making in relation to such babies and it is clear that, as described in scenarios 1 to 3, doctors, nurses and midwives vary in how they react to such a situation. In this article we want to consider some of the wider implications for the decisions we make in relation to managing births before 24 weeks of gestation.

## What are the implications for parents

The impact of a baby's death at any gestational age is a devastating experience. Parents whose baby dies as outlined in any of the three scenarios require the same postnatal care and bereavement care

as if the baby had died at term. Anecdotally, this may vary in line with local policy based on the gestation at which the baby was delivered and whether the baby showed signs of life. However inequalities definitely do arise due to the statutory UK position for parents experiencing a fetal loss, stillbirth or neonatal death (see box 2) and clearly this may make their loss even more difficult. The parents in scenarios 1, 2 and 3 will have very different experiences following the birth, and these are outlined here.

#### Box 2: Official definitions of stillbirths and neonatal deaths in England and Wales

##### Official definitions

If a baby is born, showing no sign of life, before the end of the 24th week of pregnancy, this is called a *miscarriage or fetal loss*.

If a baby is born after the 24th week of pregnancy, showing no sign of life, this is called a *stillbirth*.

If a baby is born, showing signs of life at **any** gestational age and then subsequently dies within the first 28 days of life, this is called a *neonatal death*.

#### *Birth and death certification*

Whether these babies are recorded by a clinician as being live born or not has enormous implications for parents. The parents in scenario 2 and 3 whose baby is live born but dies shortly after birth, must go to the local registry office within five days to officially register both the birth and death of their baby. They will receive official certificates for both of these events. While this is an extremely difficult experience, their baby's life is officially acknowledged and they can retain these certificates to add to their other keepsakes. In contrast the parents in scenario 1 whose baby was thought to be showing no signs of life born before 24 weeks will not receive either of these official certificates. If their baby had been born at 24 weeks gestation or later and consequently classified as a stillbirth, they would have received a legal death certificate but no birth certificate. Sands (the stillbirth and neonatal death charity) has highlighted the importance of these certificates to parents as part of the bereavement process and many hospitals across the UK provide informal birth and death certificates for parents often using those developed by Sands<sup>1</sup>. The differences relating to

legal certification also impacts on the terms used to describe babies showing no signs of life such as late miscarriage, fetal loss, and fetal death. Parents will feel strongly that they have lost a baby and not had a miscarriage or delivered a fetus at this gestation and they find the use of such terminology impersonal.

### *Maternity and paternity leave and financial support*

The decisions taken in the scenarios outlined in Box 1 will also impact on the leave and financial support available after the birth. Parents of a live born baby that dies after birth as in scenarios 2 and 3 and similarly parents of a still born baby (from 24 weeks gestation onwards) are entitled to much the same maternity and paternity leave, and maternity pay as other families who have had a new baby<sup>2</sup>. These parents are also eligible for financial support including Child Benefit and Child Tax Credit up to 8 weeks after the death and the Funeral Expenses Payment. Mothers are also entitled to free prescriptions and NHS dental treatment for 12 months and other financial aid such as Income Support. In stark contrast, the parents in scenario 1 where the baby was determined to be a fetal loss will not be entitled to any of this support. These parents can only take sick leave for as long as their GP signs them off. Sick leave related to a miscarriage is protected in the same way for the mother as sick leave for a pregnancy related illness, so it is not limited in how much the mother can take and it must be recorded separately from other sick leave. However the same protection would not be offered to the father. No additional financial support is available although despite the lack of a Funeral Payment, most hospitals will pay for the cremation of babies born showing no signs of life before 24 weeks gestation. As a consequence of these differences the parents in scenario 1 will be at much greater risk of facing financial strain on top of their grief, particularly since women from socioeconomically deprived areas are more likely to experience birth at these early gestations.

### Box 3: Impact of decision-making on parents

	Fetal loss (Scenario 1)	Neonatal death (Scenarios 2&3)
Receipt of official birth certificate & inclusion in birth statistics	No	Yes
Receipt of official death certificate & inclusion in mortality statistics	No	Yes
Eligible for maternity/paternity leave and maternity pay	No	Yes
Receipt of child benefit for 8 weeks	No	Yes
Eligible for means-tested assistance with funeral expenses	No	Yes
Free prescriptions and dental care for one year following the birth	No	Yes

### Impact on the Trust and the NHS

These variations in decision-making can have another indirect impact which is particularly concerning. In the UK only deaths that are legally registered are included in the nationally reported statistics for stillbirths, neonatal deaths (a live born baby dying before 28 days of life), perinatal deaths (a stillbirth or neonatal death); or infant deaths (a live born baby dying before 1 year of life). Consequently babies such as in scenario 1 classified as a fetal loss are excluded from these statistics, while babies in both scenarios 2 and 3 are included.

Previously we have identified that in England and Wales, in some hospitals scenario 1 was much more common than in others<sup>3</sup>. Our research found that in some regions, 4 out of 5 of these babies were classified as a fetal loss compared to other regions where only 1 in 5 was a fetal loss. This has a large impact on local mortality rates because although births before 24 weeks are very rare (less than 1 in a 1000) since their outcomes are so poor they contribute significantly to mortality statistics. This can result in those hospitals with a low proportion of babies classified as a fetal loss as in scenario 1, having up to 30% higher neonatal or perinatal mortality rates than those who classify most babies born at such gestations as a fetal loss born, even though their rates of mortality for babies born after 24 weeks are the same (see Table 1).

Table 1: Impact of variation in management of babies born at the limits of viability on mortality rates

	Hospital A	Hospital B
Total live births (all gestations)	4,000	4,000
Total neonatal deaths (all gestations)	20	26
<i>Neonatal mortality rate per 1000 births (all gestations)</i>	<i>5.0</i>	<i>6.5</i>
Total live births <24 weeks	2	8
Fetal losses <24 weeks (not included in neonatal mortality rates)	8	2
<i>Neonatal mortality rate per 1000 births (&gt;=24 weeks)</i>	<i>4.5</i>	<i>4.5</i>

These differences are not due to differences in the quality of care for babies per se but due to differences in whether these babies are reported as showing signs of life. Consequently this variation maybe masking true underlying differences in the quality of care provision between providers and this can lead to the unnecessary and inappropriate reallocation of resources and implementation of new practices.

### **Implications for the baby**

Over the last twenty years improvements in antenatal and neonatal care have led to dramatic improvements in the survival of preterm babies. However for those babies born before 24 weeks chances of survival remain extremely poor with a negligible improvement over time. Only around 1 in 50 babies survive to discharge from hospital at 22 weeks and that rises to just 1 in 5 at 23 weeks<sup>4</sup>. While there are many media stories of surviving “miracle” babies born at these gestations, those that do survive are very likely to have severe problems affecting their health and or development.

However, since there is little information nationally on fetal losses, studies of outcomes in organisations with low levels of babies reported as live born may suggest an over optimistic view of survival at these early gestations.

### **Conclusions**

At the heart of this discussion regarding the management of babies born at the limits of viability is the aspiration to ensure that at all times we act in the best interests of the family. We hope that by

highlighting the impact of practice on both parents and the NHS will allow clinicians to reflect on their own personal practice and its wider ramifications which are often unrecognised. While differences in practice are unlikely to impact on long term outcomes for these babies (as they are universally poor both across the UK and internationally), simple changes in the approach to care may provide a vital opportunity to improve experiences for parents.

As reported here, the impact of variation in decision-making has a large impact on the mortality rates calculated for Trusts and Health Boards and other health geographies. Since the World Health Organisation define the perinatal period as beginning at 22 weeks gestation it is vital that we improve our data collection on these babies and allow international comparisons to inform ways of improving care. MBRRACE-UK, who have been appointed by the Healthcare Quality Improvement Partnership (HQIP) to continue the national programme of work investigating maternal deaths, stillbirths and infant deaths, have since 2013 re-instigated the collection of information on babies born showing no signs of life from 22 weeks gestation onwards<sup>5</sup>. Although initial reporting of these babies by units has been poor it is hoped that as clinicians increasingly recognise the importance of these data, reporting will improve and allow the variation in registration of births before 24 weeks gestation to be accounted for in national mortality statistics. In the future there is the opportunity to open up the debate on whether the UK legislation should fall into line with the majority of European countries with the instigation of a 22 week gestational age cut-off to define a stillbirth.

We would welcome discussion with neonatologists and neonatal nurses with any level of experience regarding the management of these babies to further understand this challenging issue. If you are interested in helping in this way please contact Lucy Smith ([lucy.smith@leicester.ac.uk](mailto:lucy.smith@leicester.ac.uk)).



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