

# Infants born at the limits of viability: how management decisions impact on parents and the NHS

While improvements in neonatal care have significantly improved the survival of infants born prematurely, the outcomes at the limits of viability remain extremely poor. Despite the rarity of births at this early gestation, there is wide variation in clinicians' practice in the recording of these infants 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.

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### Key points

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1. Wide variation exists in clinicians' practice in whether infants born at the limits of viability are recorded as live born.
2. 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.
3. Reflection on practice may lead to improved outcomes for parents.
4. Improved national reporting of fetal losses before 24 weeks' gestation will allow reliable exploration of variations in quality of care provision between health organisations.

## Managing infants born at the limits of viability

The birth of an infant at the limit of viability (which, for the purposes of this article, includes any baby born <24 weeks' gestation) with little or no warning is a situation familiar to most clinicians involved in neonatal care. **FIGURE 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.

In all three scenarios outlined in **FIGURE 1** the clinicians involved acted in a way that they felt was in the best interests of the family. It seems clear the infant was not going to survive but the circumstances of the 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 infants 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. This article considers some of the wider implications for decisions made in relation to managing births before 24 weeks' gestation.

## What are the implications for parents?

The impact of an infant'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 it had died at term. Anecdotally, this may vary in line with local policy based on the gestation at which the infant was delivered and whether it 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 (**FIGURE 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.

## Birth and death certification

Whether these infants 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

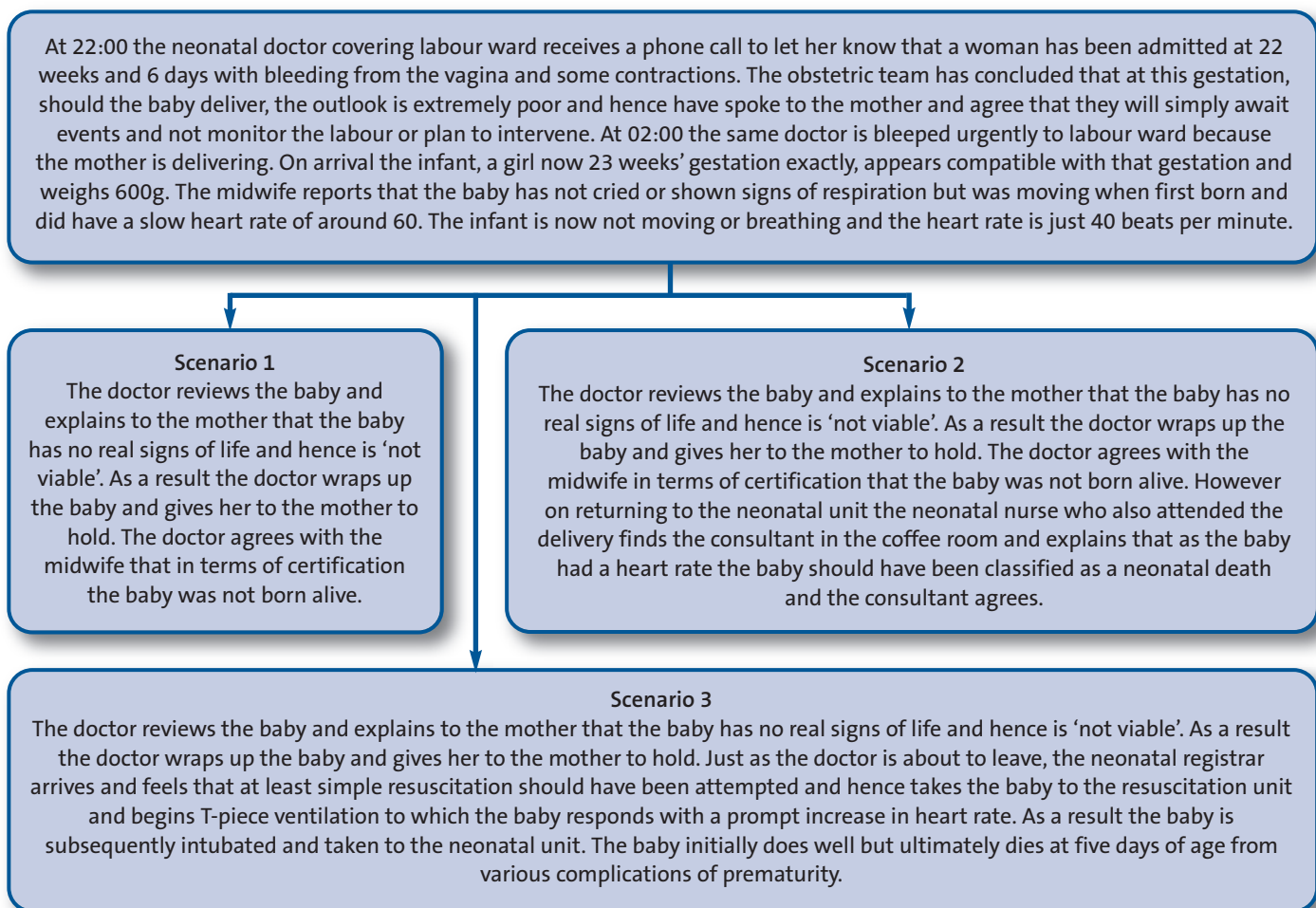


FIGURE 1 A typical clinical scenario of a baby born at 23 weeks' gestation and possible outcomes.

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 impact on the terms used to describe infants 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 FIGURE 1 will also impact on the leave and financial support available after the birth (FIGURE 3). Parents of a live born baby that dies after birth, as in scenarios 2 and 3, and similarly parents of a stillborn 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 eight 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

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*.

FIGURE 2 The official definitions of stillbirths and neonatal deaths in England and Wales.<sup>6</sup>

	Fetal loss (scenario 1)	Neonatal death (scenarios 2 and 3)
Receipt of official birth certificate and inclusion in birth statistics	No	Yes
Receipt of official death certificate and inclusion in mortality statistics	No	Yes
Eligible for maternity/paternity leave and maternity pay	No	Yes
Receipt of child benefit for eight 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

FIGURE 3 The impact of management decisions on parents.

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 infants 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.

### Impact on the trust and the NHS

These variations in decision making can have another indirect impact that 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 one year of life). Consequently infants such as in scenario 1, classified as a fetal loss, are excluded from these statistics while those in both scenarios 2 and 3 are included.

Previously the authors identified that in some hospitals in England and Wales, scenario 1 was much more common than in others.<sup>3</sup> Their research found that in some regions, four out of five of these infants were classified as a fetal loss, compared to other regions where only one in five was a fetal loss. This has a large impact on local mortality rates because although births before 24 weeks' gestation are very rare (<1 in 1,000) since their outcomes are so poor they contribute significantly to mortality statistics. This can result in those hospitals with a low proportion of infants classified as a fetal loss, having up to 30% higher neonatal or perinatal mortality rates than those who classify most infants born at such gestations as a fetal loss, even though their rates of mortality for infants born after 24 weeks' gestation are the same (FIGURE 4).

These differences are not due to differences in the quality of care for infants *per se* but due to differences in whether these infants are reported as showing signs

	Hospital A	Hospital B
Total live births (all gestations)	4,000	4,000
Total neonatal deaths (all gestations)	20	26
Neonatal mortality rate per 1,000 births (all gestations)	5.0	6.5
Total live births <24 weeks' gestation	2	8
Fetal losses <24 weeks (not included in neonatal mortality rates)	8	2
Neonatal mortality rate per 1,000 births (≥24 weeks' gestation)	4.5	4.5

**FIGURE 4** The impact of variation in management of infants born at the limits of viability on mortality rates.

of life. Consequently this variation may be 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 infant

Over the last 20 years improvements in antenatal and neonatal care have led to dramatic improvements in the survival of preterm infants. However for those born before 24 weeks' gestation, chances of survival remain extremely poor with a negligible improvement over time. Only around one in 50 infants survive to discharge from hospital at 22 weeks' gestation and that rises to just one in five at 23 weeks' gestation.<sup>4</sup> While there are many media stories of surviving 'miracle' infants 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 infants 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 infants born at the limits of viability, is the aspiration to ensure that healthcare professionals act in the best interests of the family at all times. By highlighting the impact of practice on both parents and the NHS, it is hoped that clinicians will reflect on their own personal practice and its wider ramifications, which often go unrecognised. While differences in practice are unlikely to impact on long-term outcomes for these infants (as they are universally poor both across the UK and internationally), simple changes in the approach to care may provide a vital

- Remember the wider implications for the NHS and parents when classifying an infant's birth before 24 weeks' gestation.
- Parents may welcome the receipt of a local birth certificate even when the birth does not meet formal registration criteria.
- Instigating systems to ensure recording of deaths of infants born from 22 weeks' gestation or even earlier will help to improve the reporting of perinatal mortality in the UK.

**FIGURE 5** The impact of practice on both parents and the NHS: learning points.

opportunity to improve experiences for parents (FIGURE 5).

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 Organization defines the perinatal period as beginning at 22 weeks' gestation, it is vital that data collection on these infants is improved to allow international comparisons to inform ways of improving care. MBRRACE-UK (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries), who has been appointed by the Healthcare Quality Improvement Partnership (HQIP) to continue the national programme of work investigating maternal deaths, stillbirths and neonatal deaths, has re-instigated (since 2013) the collection of information on infants born showing no signs of life from 22 weeks' gestation onwards.<sup>5</sup> Although initial reporting of these infants 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 in line with the majority of European countries with the instigation of a 22-week gestational age cut-off to define a stillbirth.

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

## Declaration

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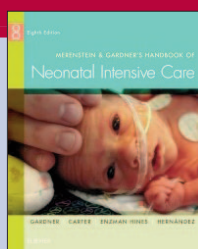
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## Book review

### Merenstein and Gardner's Handbook of Neonatal Intensive Care, eighth edition

Sandra Gardner, Brian Carter, Mary Enzman Hines and Jacinto Hernández  
Elsevier, 2015. ISBN: 978-0-323-32083-2  
£57.99, paperback, 1,008 pages



As a neonatal grid trainee constrained by busy rotas, e-Portfolio and a toddler, I welcomed the opportunity to review a textbook that might provide a concise, comprehensive and up-to-date account of neonatology.

When I first opened the book I was a little disappointed to see a sea of text, highlighted in purple at certain points with a few tables and diagrams. I am very much a visual learner and the absence of pictures really deterred me from engaging with it. However, I decided to challenge the book (and myself) and read the chapter on Fluid and Electrolyte Management, a topic that I have always struggled to fully comprehend.

I have to say that my first impressions were wrong. The combination of formulas

and clear explanations in conjunction with the highlighted purple text really does aid the learning process; for the first time I feel I have actually grasped sodium imbalance! Even in a theoretical chapter such as this, the 'parent teaching' section included a list of important areas to cover when advising a parent of a child with an intravenous line, demonstrating the broad and holistic view the book brings to every element of neonatology. The book covers core topics in six units:

1. Evidence-based practice
2. Support of the neonate
3. Metabolic and nutritional care
4. Infection and haematologic diseases
5. Common systematic disease
6. Psychological aspects of neonatal care.

Unit six is an especially welcomed component covering topics such as 'Families in crisis' and 'Discharge planning'. These areas are often covered superficially in core curricula yet demand compassion and understanding among the neonatal multidisciplinary team.

Having read the book in full, I feel that it will be useful; a book that can be dipped in and out of. The text is clearly written enabling easy retrieval of key information with core concepts covered in substantial depth. As it is American, some of the guidelines and current practice recommendations vary from that of the UK, however, in general the book is highly applicable to UK readers. The multidisciplinary and parent perspective is insightful, having been achieved by co-authorship with nurses and physicians. The book lends itself to any healthcare professional involved in neonatal care.

Although a little heavy to carry around on a daily basis, it makes for an ideal desktop reference.

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