



Judith Schott

judith.schott@uk-sands.org



Alix Henley

Sands Improving Care Team,
Sands, the stillbirth and
neonatal death charity

Care after a perinatal loss: the Bereavement Care Network

Every day in the UK 17 babies are stillborn or die within the first four weeks of life. Six thousand five hundred babies die each year before, during, or shortly after their birth. These numbers have changed little in the last decade.

There is a great deal of work to be done to improve our understanding of the causes of perinatal deaths and of how these deaths might be prevented. Meanwhile, every year, thousands of parents are devastated by the death of their babies.

Although nothing can ease the pain that bereaved parents experience, good care can make an important difference. Poor or insensitive care increases parents' distress and can affect their long-term wellbeing.

Parents

Parents consistently report that they remember in acute detail everything that happened around the time of their baby's death. They often have clear and precise recall of their surroundings; the colour of the walls, the pictures, the equipment in the room, the view from the window. They also have especially vivid memories of the people who were there, how they behaved, what they said and didn't say, and what they did or didn't do.

Parents' memories of the events surrounding their baby's death are often played and replayed over the following months, and sometimes over many years. Memories of good and thoughtful care and of individual acts of kindness and compassion can bring some comfort in the months and years to come. However, memories of poor care, thoughtlessness or insensitivity are also replayed over and over and can cause pain and distress well into the future.

It is important to note that care for parents whose baby dies has improved out of all recognition over the last 30 years. Sands, the stillbirth and neonatal death charity, has played a large part in helping health professionals to understand and meet the needs and wishes of bereaved parents. The Sands Guidelines for professionals, *Pregnancy loss and the death of a baby*¹, are widely recognised as the benchmark for good practice in bereavement care. Many staff have had little or no training in this area, either as undergraduates or as qualified practitioners, so Sands' training in bereavement care for health professionals is in great demand.

Health professionals

Delivering a stillborn baby, or caring for a baby who dies in the neonatal unit, is extremely distressing for staff. Caring for the baby's distraught parents is also stressful and demanding. Dedicated practitioners in many areas have gone out of their way to develop sensitive and innovative practices and many bereaved parents have benefited as a result. However, many members of staff feel ill-equipped to care for these parents and good care is not universal.

In many places bereavement care is also not perceived as a core part of the service. A recent small sample of maternity units showed that while 47% have one or more designated bereavement midwives, 53% do not². Units with more births (and therefore more perinatal deaths) are no more likely than smaller units to have a bereavement midwife. Many bereavement midwives are part-time, or only have a certain number of hours allotted to this part of their work. In many units the demanding work of a bereavement midwife is done by staff who do not have a specific title and do not receive the same recognition or remuneration as a bereavement midwife.

Staff who specialise or have a particular interest in bereavement care therefore often work in relative isolation and without proper support. Few have contact with colleagues in similar roles working in other maternity units.

A new network for bereavement care staff

In 2009 Sands proposed that there should be an on-line network that would enable midwifery, neonatal staff, nurses and health visitors who are involved in caring for bereaved parents to share ideas and good practice and to exchange support. This idea was welcomed by the Royal College of Midwives, which agreed to host the network, and by Bliss, the special care baby charity. The National Maternity Support Foundation generously donated money to cover the costs of the website design.

The Bereavement Care Network was launched in September 2009 at a joint conference, *Uncertainty and loss in maternity and neonatal care*, organised in London by the RCM, Sands and Bliss.

As a first step, all staff with an interest in perinatal bereavement care were invited to email

the network if they wanted to join. We received over 100 applications in the first few weeks and emails are still arriving. We now have over 160 applications.

The Bereavement Care Network went live on-line in April 2010. It offers members an opportunity to share good practice and procedures, exchange ideas, and provide informal support. It will also be a way for the RCM, Sands and Bliss to keep network members informed about relevant information, developments and resources. It will not be used for any other purpose.

If you are a midwife, nurse, health visitor, student nurse or student midwife, or a member of another health profession and you provide, or are interested in, the care offered to parents whose

baby dies, you can apply to join the network via the website at <http://bereavement-network.rcm.org.uk/login/>

Following the success of the 2009 conference, another joint conference organised by the RCM, Sands and Bliss is to be held this year in London on Thursday 16 September. For information about this year's conference, *Uncertainty and loss in maternity and neonatal care*, please go to Event List at www.profileproductions.co.uk.

References

1. Schott J., Henley A., Kohner N. Pregnancy loss and the death of a baby: guidelines for professionals. Sands. 2007.
2. Bereavement Care Report. Sands. 2010. In press.

iNO Care – European Inhaled Nitric Oxide Registry

Inhaled nitric oxide (iNO) is used in the treatment and diagnosis of a variety of cardiorespiratory disorders in children. It is licensed for use in term and near-term neonates (≥ 34 weeks' gestation) with hypoxic respiratory failure associated with clinical or echocardiographic evidence of pulmonary hypertension, in order to improve oxygenation and to reduce the need for extracorporeal membrane oxygenation (ECMO). It is being increasingly used in older children and those with cardiac disorders.

The European Inhaled Nitric Oxide Registry is an European Collaboration which was established originally by a group of interested clinicians in 2006. As a Steering Committee member of the European Inhaled Nitric Oxide Registry I would like to invite clinicians to join this project. The Registry was formally launched in September 2009. Anonymised data is submitted online using a web-based data form and held securely in a central data repository managed by MedSciNet, an internet database provider who also runs other similar projects such as the Swedish PNQ National Perinatal Quality Registry and a variety of high profile international randomised controlled trials (<http://www.medscinet.net/>).

The aim of the Registry is to collate data about patient demographics, indications for treatment, delivery and administration of iNO, thresholds for treatment, concomitant treatments, potential adverse effects of therapy and clinical outcomes. The data from patients will be divided into three subsets:

- Neonatal without cardiac diagnosis
- Neonatal or paediatric with cardiac diagnosis
- Paediatric without cardiac diagnosis

Specifically, these data will allow:

- Promotion of consistent, high standard, clinical management among clinicians using iNO.
- Monitoring of the range of indications for which iNO is used in routine clinical practice, which may itself inform regulatory bodies about prioritising areas for drug licensing.

- Identification of adverse events associated with iNO therapy (a post-marketing surveillance role).
- Generation of research hypotheses that can be tested formally in the context of properly designed clinical trials.
- Support of future clinical trials of iNO therapy by, for example, informing discussions about sample size calculation.
- Monitoring of trends of iNO usage in relation to other cardio-respiratory therapies such as extracorporeal membrane oxygenation.

To date information has been collected in over 300 children treated with iNO from nine neonatal and paediatric intensive care units in seven countries (including Liverpool Women's Hospital, the Royal Victoria Infirmary, Newcastle and the Royal Maternity Hospital, Belfast). Data from the pilot phase of the Registry has been presented at various international scientific meetings (ESPR, WPICC) and an original paper has recently been published (*Acta Paediatrica* 2010, <http://www3.interscience.wiley.com/journal/123313104/abstract>). We have demonstrated that this type of information can be collected and reported successfully, and believe that it has the potential to add to the body of observational research on iNO therapy.

I hope that you will consider joining the Registry (it is free to join and submit data). At present the Registry is funded through an unrestricted educational grant from Linde Gas but we plan to secure independent (non-commercial) EU funding in the future. You can get more information by contacting me or visiting the test version of the Registry at www.medscinet.net/inotest/ using the following login details:

Username: test

Password: test

I look forward to welcoming you to the Registry.

Dr Nim Subhedar (Liverpool Women's Hospital, UK)
nim.subhedar@lwh.nhs.uk