

Bereavement support in neonatal intensive care

Bereavement support is an important aspect of continuing care that neonatal units should make available to all families following the death of their baby. This article describes a neonatal bereavement support service operating in a tertiary neonatal unit. Neonatal units wishing to establish or expand their existing bereavement service can use this article as a template.

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It is well documented that the death of a baby has a profound and far-reaching effect on family members^{1,2}. There is also some evidence that there can be distressing emotional effects on staff caring for dying babies³. In response to recognition that support following child bereavement is important, St Mary's Hospital neonatal unit established a dedicated bereavement service in 1995. The service has since evolved to provide a comprehensive range of family and staff support. The bereavement team comprises three experienced neonatal sisters and a neonatal counsellor, who have all undertaken counselling courses or professional development programmes and participated in educational workshops run by the Child Bereavement Trust (CBT)⁴. They have also attended the CBT Train the Trainer Development Workshops, which enables them to train and support other staff members.

The Bereavement Support Service has provided care for many families since its inception in 1995. The unit at St Mary's Hospital is a tertiary neonatal unit, part of the Greater Manchester Neonatal Network, with approximately 600 admissions annually and about 50 deaths per year. The bereavement service is an essential means of offering families of these infants adequate psychological and practical support following the death of their baby.

The aims of the service are to:

- provide care for families during the terminal phases of their baby's life
- enhance the care and support offered to grieving families including siblings
- provide support and education for staff in this demanding area of work
- seek the views of families and staff members for means of improving the service.

In recognition of the service delivered at St Mary's, the neonatal bereavement team received an award for outstanding bereavement support from the Child Bereavement Trust in November 2004.

Care in the immediate period prior to death

The death of a child is an exceptionally painful loss for parents to live with. The literature suggests that care received by babies during their hospitalisation prior to their death, can have a profound impact on the grief response of their bereaved parents^{5,6}, therefore this period should be handled sensitively and focus on the needs of parents. The aim of the team is to empower all unit staff to care for families around the time of the death of a baby, depending on their experience.

Frequently the death of infants on the neonatal intensive care unit follows the decision to withdraw care⁷. In other instances death is anticipated due to the clinical condition of the baby. As such there is often the opportunity to explore the option of a blessing or appropriate religious ceremony with parents. If parents would like this to occur, they are encouraged to invite family and close friends to a ceremony, which takes place on the unit. Most hospitals in the UK have on-site chaplains and access to religious support. These resources should be utilised if the parents so wish.

Ideally, bereavement support begins during the terminal phases of an infant's life. A member of the bereavement team and the counsellor introduce themselves. Some parents choose not to meet with the team at this time and this is respected. All the nursing members of the bereavement team are also clinically based on the

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Key points

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1. Bereavement support on the neonatal unit should be available for all families following the loss of their baby.
2. A dedicated area of the unit should be developed into a bereavement suite to enable families to have privacy during the terminal phases of their child's life and also following the death of their baby.
3. Families should have access to a high standard of bereavement follow-up care.
4. In addition to supporting families, a neonatal bereavement service should also provide appropriate support and education to staff working on neonatal units.



FIGURE 1 An opportunity for the family to say 'Goodbye'. Illustration reproduced with permission from 'A Photographic Memory. Guidance for Professionals' published by The Child Bereavement Trust.

neonatal unit, and are available to support unit staff during the terminal phase of an infant's illness. The families are allocated to the team member who has had the most contact with them prior to the death of their baby, or to the team member with the lightest case load if the family is not known to any of them. The bereavement team will discuss with families about the involvement of siblings and other family members, who on many occasions have not yet seen the baby (FIGURE 1). They will inform the parents about the possibility of spending some time in the bereavement suite, offer to take pictures of the baby and give any practical support that the family may require.

Some parents request that care of their baby be withdrawn within the privacy of the bereavement suite so they can spend the last minutes or hours of their baby's life unfettered by the trappings of technology. If it is appropriate, the baby is moved to the suite with the use of a portable ventilator and infusion pumps by the medical and nursing team. The suite is equipped to be able to provide intensive care and so the care of the terminally ill baby continues within the suite. Other parents prefer to transfer to the suite after their baby has died.

The bereavement suite

The bereavement suite is situated adjacent to the neonatal intensive care unit. It was designed six years ago and partly funded through charitable donations. Parents,

many of whom had experienced neonatal bereavement in the past, were consulted in the planning and design of the suite. It includes a kitchen, bathroom and a sitting room. The main living area has specially designed lighting and appropriate soft furnishing. There is a double sofa bed in the sitting room. Also stored within the suite are a selection of baby clothes, baby baths, towels and bed linen.

The needs of siblings have been taken into account, with toys for various age groups provided within the suite. There is a memory book for parents to write inscriptions in about the memories they have of their baby. Parents can also read what other bereaved families have written and have often commented that it makes them feel that they are sharing their grief with others and that it is good to know it is not abnormal to feel as they do during this difficult time.

There are two telephones, one of which is an internal line to provide contact with the neonatal intensive care room; the second is an external line to enable families to make direct contact with relatives and friends outside the hospital, without having to be connected via the hospital switch board.

Bereavement support in the immediate period following death

The immediate period following death is a very sensitive time for families. Parents often describe feelings of sadness because of their inability to help and their lack of

control over what was happening while their baby was dying. It is important to help them feel that they can contribute, and indeed they should be encouraged to participate in decisions and activities following their baby's death. A member of the bereavement team is made available to stay with the family if support is required. Relevant literature is given to the parents, including a locally designed and produced leaflet, entitled "Information for parents following the death of their baby". This contains practical information about regulations in the local vicinity, and explains briefly about death and dying. SANDS' leaflets – "Saying goodbye to your baby", "What has to be done", "Support for when your baby dies", "Mainly for fathers" and if appropriate a SANDS leaflet "The loss of your grandchild" are also made available to the family.

Both the birth and death need to be registered and this is often the first practical thing parents are able to do. Parents are also encouraged to take pictures, and spend time with their child. The bereavement team provide a list of poses they may want to use and will help in taking the pictures as this can be difficult for parents. A member of the team will keep films or pictures if parents decide that they don't want to keep them at the time, as this leaves the option to collect them in the future if they change their mind.

Most of the babies will not have worn any clothes during life. Parents are encouraged to select at least two sets of baby clothes from those kept in the bereavement suite. The first set they can dress the baby in soon after death, and then they can select a second set for use later on. This means that they will have an item of clothing that has been worn by their child that they can keep.

Some families are not aware that it is possible to have their baby at home for a short time prior to the funeral, and parents are encouraged to do so if it is their wish. To enable the parents to spend a longer time with their baby, the infant can be placed in a cold cot. It looks like a conventional postnatal ward cot, but below the cot where the cupboards are usually located, is a motor which cools the base of the cot to between 0-1°C. The base is covered by a blanket onto which the baby is placed. These cots are made to order by a company that specialises in temperature-controlled environments Demeva Limited⁹.

Some families choose to take their baby home immediately after death. If this is appropriate, members of the team facilitate this, by making sure all the necessary documentation is completed as quickly as possible. The bereavement team have written guidance regarding this procedure, which is available on the neonatal unit.

Funerals and blessings

The team helps the family with planning the funeral. There is also a Directorate Bereavement Officer who can give more detailed advice about funerals, and can liaise with the local hospital regarding arranging a funeral for parents nearer to home.

A hospital funeral is arranged if the parents feel unable to arrange their own service. Most parents will not have arranged a funeral before and will be unsure of what to do and may appreciate the guidance and suggestions that the bereavement team provide. The team discusses with parents what they might like to include in the service to remember their baby. Some of the suggestions include, where the funeral takes place, headstones, flowers, and songs and readings for the service. A member of the bereavement team attends the funeral and a non-denominational card is sent on behalf of the unit to the family.

Provision of keepsakes and mementoes

A memory box and a keepsake bag (FIGURE 2) are given to all parents. Some parents choose not to have any reminders and this is respected. The memory box contains a

list of suggested pictures that parents could take, a small teddy and an information leaflet listing useful organisations that provide support to bereaved families (FIGURE 2). The teddy is given to siblings as a gift from the unit. Parents choose a blanket of their choice from the selection available in the bereavement suite to place their baby in, this is later placed in the box. The keepsake bag also contains most of the items that were used as part of the process in caring for their child – cord clamp, cot cards, name bands, blood pressure cuffs, ECG leads and toys. It also contains hand and foot prints and a lock of the baby's hair.

The bereavement team can also provide a diary of the baby's life on the unit. Many parents find it very comforting to have a written description in the form of a personal account of the day-to-day events that occurred while their baby was alive.

Siblings

The bereavement needs of siblings are important¹⁰. The team discusses with parents how to explain to siblings about the death of their brother or sister. There are resources for parents (videos and books) as well as books specifically designed for young children to help them understand. Team members take books and videos on home visits to help to explain things further to siblings. Many parents have said they would not have involved siblings but for the advice of the team, and they are now grateful that they did, because as a result of this intervention, the lost sibling is discussed openly within the family.

Communication

There is a direct confidential telephone line for bereaved families to contact the neonatal bereavement counsellor. There is also a 24-hour dedicated telephone to contact nursing members of the bereavement team. The answering machines on these two phones are checked daily. Parents are also given the email address for the bereavement team so that they may send emails to the team if they wish. There is a link worker service for parents whose spoken language is not English, to ensure the service is accessible to all patients irrespective of the language spoken. The families can maintain contact with the team for as long as they wish, and some parents find it useful to continue to retain a link to the neonatal unit for many years, as the hospital staff are usually the only other people who knew their child.

Financial advice and benefits

The team can give advice to parents about a range of financial matters including maternity leave benefits, returning to work, and social benefits. There is also a charitable bereavement fund, which is used for funding some of the resources used for parents. In some circumstances, if appropriate, the team will liaise with social workers in order to obtain money to fund headstones and respite breaks for parents.

Follow-up

As St Mary's is a regional unit, many of the bereaved families live in other parts of the region. The bereavement team will visit any family irrespective of the area they reside in. Parents are seen very regularly in the immediate period following death, but contact is gradually tailed off as time elapses, as families feel the need to 'move on'. The period of contact is very variable and is dependent on the needs of the individual family. Very often one parent requires on-going support for some time after their partner has come to terms with their loss¹¹. Flowers are sent to the family about 6 weeks after the death to let them know they are still being thought of.

Although counselling is provided by the team, the option for referral to professional counselling is also discussed with parents if the care of families becomes complex. The team helps to arrange/coordinate follow-up visits with other health professionals if the family requires this support. For example, arranging a follow-up visit with an obstetrician if parents would like to



FIGURE 2 All bereaved parents are given a memory box to store mementoes of their baby.

discuss problems that may have arisen during pregnancy, or informing a neonatal consultant that the family would like to defer an appointment for a follow-up visit, until they feel more able to cope.

There is an annual service of remembrance at the chapel in St Mary's hospital. Families are formally invited back for the first two years following the death of their infant and after that, they attend if they wish. At the service, the names of the babies are read out, and for each child, a candle is lit, which the family may take away.

Ongoing and future service development

The aim of the service is to continue to provide a high standard of care to bereaved families and to provide support and education to staff. Regular audit is one of the means by which service evaluation can be achieved¹². An audit of the views of parents who have used the service was undertaken two years ago. Some parents said they found it difficult returning to the unit as the sounds and sights of the neonatal environment brought back painful memories. In response, many follow-up bereavement appointments with the consultant neonatologist are now made away from the unit. A rolling audit of parental views and uptake of the service is

being established.

There are regular education sessions for doctors and nurses as well as development of written guidance, which is regularly updated according to parents' needs and current best practice in the area. This is supported by a consultant neonatologist (NEE-O) who has an interest in care and support of bereaved families. The team is keen to improve support provided to families from an ethnic minority background, and is investigating the presentation of information given to these families following death.

The team is also developing qualitative research into provision and delivery of bereavement support in the neonatal intensive care arena.

Conclusion

Neonatal intensive care units should aim to provide this essential service to bereaved families, as families leaving the neonatal unit after the death of their baby, require the same amount of consideration as those families fortunate enough to be taking a baby home.

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