

Generally parents value and find comfort in photographs and mementos of their demised twin and appreciate having a record of both of the twins together. With this in mind it is important to inform parents quickly if the demise of one twin is anticipated.

'one thing which I did find difficultI was put next to a lot of twins'

7. Handle cot occupancy sensitively

Cot occupancy will often present a challenge on the unit. There will almost never be sufficient flexibility to provide all parents with ideal accommodation for themselves and their babies. However, there are a number of practical steps that can be taken to make the situation the best it can be. It is painful for parents who have lost a twin to be surrounded by twins and to see them being visited and their 'special twin status' celebrated by their visitors. Wherever possible (and after consultation with the parents) it might help if a surviving twin can be placed in a ward or bay where there are no other sets of twins.

8. Prepare parents for discharge from hospital

Some parents spend a long time on the neonatal ward while their surviving twin is cared for. The time of discharge from hospital back into the 'real world' can be a difficult and stressful time. Offer bereavement support at this time and provide information on local (e.g. buddy groups) and national organisations that parents might want to contact. Parents should also be given a follow-up appointment to meet with a named consultant at this time.

More detailed information and guidance is available from:

<http://www.neonatalresearch.net/butterfly-project-death-of-a-baby-from-a-multiple-pregnancy.html>

Resources

MBF – <http://www.multiplebirths.org.uk/>

CLIMB – <http://www.climb-support.org/>

We welcome comments on these guidelines. Please direct them to nicholas.embleton@newcastle.ac.uk
Updates available www.neonatalresearch.net/butterfly_project

These guidelines were developed with the support of Sands (Stillbirth and neonatal death charity) and The Multiple Births Foundation and are endorsed by the European Foundation for the Care of Newborn Infants

EFGNI european foundation for the care of newborn infants

Sands
Stillbirth & neonatal death charity

THE MULTIPLE BIRTHS FOUNDATION
MBF

tiny lives
SPECIAL CARE BABIES

ACADEMIC HEALTH SCIENCE NETWORK
NORTH EAST AND NORTH CUMBRIA



Bereavement from a multiple pregnancy

Guidelines for health professionals



This work was funded by
North East and North Cumbria Academic Health
Science Network (AHSN)
and the Tiny Lives Trust

Introduction



Parents expecting twins or higher order births are more likely than those expecting a singleton to experience a bereavement. Health professionals working in midwifery, obstetric and neonatal care play a key role in supporting parents when this happens. When parents lose a singleton or all of the babies from a multiple pregnancy it is clearly recognised as a tragedy, but when one twin survives the parents face a complex situation: mixed emotions of enormous grief for their demised twin and joy at the birth of their surviving twin.

'[we] didn't know how to feel. Your emotions are all over the place'

'[I'm] always scared of saying the wrong thing'

Sometimes staff worry about 'saying the wrong thing' at this time. However, parents really value the empathy and support they receive from staff in these circumstances. The importance of this role should not be underestimated.

This guidance, derived from work we have done with parents and staff, is intended to offer practical advice to help staff provide parents in this situation with support before, during and after delivery.

1. Recognise twin status

Parents appreciate it when staff acknowledge that a surviving baby is a twin and find it hurtful when it seems to have been forgotten. It is important for staff to establish quickly whether or not the parents want their surviving baby to be recognised as a twin. If they do, find out the name of the baby(ies) who died and refer to them by name during conversation.

'it was almost like – oh he's not a twin anymore....'

It might be helpful to use a symbol (for example a butterfly) on the surviving baby's cot to indicate to staff and other parents who have experienced a similar loss, that the baby is a twin.

2. Acknowledge the bereavement

Parents often feel that their loss is underestimated because of a tendency of others to try to be positive and focus on the surviving twin. Generally parents welcome the opportunity to discuss the loss of the demised twin and also 'permission' to grieve for their loss, while celebrating their surviving baby.

'people say you're lucky to get one....we wanted two, we were having two'

3. Provide emotional support

Parents value the empathy and support they receive from staff during a time when they are very vulnerable. Often staff are the only people, other than the parents themselves, to have 'known' the twin who died. This can make the bond between parents and staff special: the importance of the human interaction between staff and parents was a very strong theme in our study. However, it is important to recognise that staff themselves have busy jobs and cannot function as counsellors or psychologists. It is important that staff recognise their limitations but are still aware of the enormous help they can provide to parents.

4. Provide appropriate information

Ensuring parents are provided with accurate information and support is important. Parents report that they appreciated being 'kept in the picture' and that this gives them a sense of empowerment and of

having some control over decisions being made.

Provide parents with as much information as possible about what to expect and plenty of time so that they can make informed choices. For example, if a twin has died in utero, prepare the parents for how the fetus is likely to look at delivery. Parents are unlikely to retain all the information they are given at this time when they have experienced the recent trauma of losing a twin. Written information and/or encouraging parents to make their own notes may help.

'...we were totally informed, they didn't try and hide anything....you have to hear the honest truth'

5. Provide continuity

Research shows that parents really appreciate having continuity of staff and seeing familiar faces. Where this isn't possible due to the practicalities of staffing a busy unit, it is very helpful if health professionals ensure that information is communicated effectively between staff. Parents find it painful to have to retell different individuals about the death of their twin or for staff not to realise that their baby is a surviving twin. To avoid this, ensure that you have appropriate information to hand before approaching the parents.

'a lot of days it was a new nurse.... [meant] going through it a lot'

6. Offer memory making

Where possible photographs should be taken of both of the twins together and of the twins with their family. Keep copies of these photographs (and any other mementos) as sometimes parents don't want them at the time, but regret not having them later.