

Bereavement from a twin pregnancy Guidelines for health professionals

These guidelines arose from a research study that identified a need for guidance for health professionals supporting parents after the death of a baby from a twin or triplet pregnancy. They were developed in collaboration with health professionals working in this field. They are a guide only, and are not intended to be prescriptive.

We welcome comments on how these guidelines can be developed and improved. Please direct these to Dr Nicholas Embleton (Consultant Neonatal Paediatrician) nicholas.embleton@newcastle.ac.uk

Updates and foreign language versions maybe available from our website www.neonatalresearch.net/butterfly-project

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Summary

Families who have lost a baby from a twin pregnancy[†] face the difficult challenge of dealing with the bereavement, while often simultaneously feeling anxious about the prognosis for a surviving baby. Research has shown that health professionals often feel they lack confidence in supporting parents in this situation. Most staff working in neonatal or midwifery care will find themselves in the position of supporting parents who have suffered a bereavement from a twin pregnancy at some point, yet very few will have received training focused on this issue. The issue is also relevant to staff working on postnatal wards and in primary care. This guidance is intended to offer practical advice to help staff provide parents in this situation with support before, during and after delivery. The guidance is based on an in-depth qualitative study that explored the views of parents who had experienced a bereavement from a twin pregnancy¹. This study identified a number of positive behaviours and actions that staff can adopt that parents find helpful:

1. *Recognise twin status*

Parents generally appreciate it when staff recognise that their surviving baby is a twin.

2. *Acknowledge the bereavement*

Parents usually welcome the opportunity to discuss the loss of the twin who died.

3. *Provide emotional support*

Parents really value the empathy they receive from staff when one of their twins dies.

4. *Provide appropriate information*

It is very important to give parents access to information on an ongoing basis.

5. *Provide continuity*

Parents appreciate continuity of care where possible and seeing familiar faces.

6. *Offer memory making*

Parents find comfort in mementoes of both their twins.

7. *Handle cot occupancy sensitively on the neonatal unit*

It can be painful for parents who have lost a twin to be surrounded by other twins.

8. *Prepare parents for discharge from hospital*

Parents can find the discharge from hospital of their surviving twin difficult.

[†] The term 'twin' is used for simplicity but is understood to mean 'twin, triplet or higher order multiple' throughout.

1. Richards J et al 2015 Parental perspectives on the perinatal loss of a co-twin: A qualitative study BMC Pregnancy & Childbirth 2015;15:143

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'The important ingredient of care that has become diminished in our understandable 20th century drive for science, evidence, and technology is one simple word, and that word is kindness. Of course, technological advances are to be welcomed, and in healthcare we can and should strive to be as technically advanced and scientifically correct as we humanly can. Yet in the 21st century we also need to work more on the words that convey kindness and service'

Neal Maskrey <http://blogs.bmj.com/bmj/2014/07/01/neal-maskrey-the-importance-of-kindness/>

Introduction

This guidance is specifically aimed at midwifery, obstetric and neonatal staff working 'on the shop floor', rather than those working in more formal counselling or specific support roles. This is important because research has shown that the way in which clinical staff relate to parents when they lose a baby from a twin pregnancy at any stage during the pregnancy or shortly after delivery has a major long term impact on their experience of a difficult and painful time.

When parents lose a singleton baby or both babies from a twin pregnancy it is clearly recognised as a tragedy. However, when one twin survives the parents face a much more complex situation². Parents experience mixed emotions of enormous grief for the twin who died along with hope and joy at the birth of their surviving twin. Much of the guidance available for staff supporting parents to cope with the loss of a singleton baby also applies to parents dealing with the loss of a baby from a twin pregnancy. This guidance focuses on issues specific to twin pregnancies. When a parent loses a baby from a twin pregnancy they might have much more contact with neonatal staff than is the case with a singleton loss. In many cases the other twin delivers prematurely meaning parents remain in close contact with the hospital for weeks or months. Where the surviving twin is born close to term and does not require prolonged hospital stay, it is equally important for staff to be aware of the issues that arise, including the need for staff to act in an empathic and supportive manner. There are a number of specific circumstances that parents might find themselves in when they suffer a loss of one baby from a twin pregnancy or when one or both twins are very sick. In addition, parents who have babies cared for in hospitals other than their local unit face additional challenges¹.

The guidance is based on the findings of an in-depth qualitative research study that explored the views of parents who have experienced a bereavement from a twin pregnancy¹. The study identified a number of positive behaviours and actions that staff can adopt and that parents appreciate, as well as things that parents find upsetting and insensitive. These are summarised in this guidance. Examples of words or phrases that we think parents will find appropriate based on what they have told us are also provided. Of course, each situation needs to be judged individually and every member of staff must find their own way of relating to families that feels right for them. Conversations and interactions must be tailored to the needs of that family in particular. Thus this document should be considered as guidance and not prescriptive advice.

The guidance focuses on what staff can do to support parents after the death of a twin. However, the needs of staff must not be overlooked. There is a need for staff to offload and talk through challenging situations they have experienced. Provision for staff to reflect on the emotional impact of their work should be made within the Unit. Although informal peer support appears to be important to most staff, consideration should also be given to providing some form of mentoring system so that less-experienced staff can be supported by and learn from those with more experience. Regular de-briefing sessions could be scheduled. All staff should have access to counselling services and know how to access these, if required. Be alert to colleagues who might be having a particularly tough time and struggling to cope and be aware of the types of support available locally.

Specific areas of good practice when supporting parents who have suffered a bereavement from a twin pregnancy that we identified are provided below.

1. Recognise 'twin status'

Most parents value continued acknowledgement that a surviving baby is a twin. It is important for staff to establish whether or not the parents want their surviving baby to be referred to as a twin. Find out the name of the baby who died and ask the parents if they prefer for you to refer to them by name during conversation, or if they would prefer you to refer to them in another way. Where you can, find out the baby's name from the baby's notes and by speaking to other staff before you speak to parents. If parents have a clear preference make sure this is recorded somewhere (along with the baby's name) and passed on at staff handover.

You could say ***'I know this must be a really difficult time for you. Some parents want the baby they have lost to be remembered, but others find it painful to be reminded. If you can tell me what is helpful for you, I can make sure the other staff know. If you don't know what you want us to do just now it doesn't matter. We can talk about it another time.'***

Many parents told us that the loss of the 'special status' that is associated with having twins, and which had been developing over several months, was particularly painful. They appreciated it when staff recognised that their surviving baby was a twin and found it upsetting when it seemed to have been forgotten.

You could say ***'When you look at [name of surviving twin] it must make you think of [name of twin who died]'***.

Linked to the above, we think 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. This may help to remind staff and prevent unintentional painful comments being made. Explain to parents what this looks like, and why it is used. Ask them if they would like this, and ask them if they would like the name of the twin who died to be written on it, or if they would like to annotate it in some other way (e.g. putting a photograph on it). Because this has not been explored in a research study, we do not know yet what parents will think of this, so we plan to do further work with parents to find out.

You could say ***'We use these (butterfly) symbols that we put on the cot of a baby who has lost a twin to indicate to staff and other parents that this baby is a twin. Is that something you would like us to do for your twins?'***

When the twin loss occurred early in pregnancy it is more common for these issues to be overlooked, so conversations need to account for these differing experiences. It might be helpful to place a butterfly symbol on midwifery and/or obstetric notes to indicate that a baby is a twin, if this is what the parents want.

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 twin who died, at whatever stage of pregnancy the loss occurred, and also 'permission' to grieve for their loss, while celebrating their surviving baby.

Staff have also reported feeling that sometimes they have focused too much on the surviving twin and regret not giving parents the opportunity to reflect on their bereavement.

You could say ***'It's completely normal for you to feel terrible sadness about the death of your baby, but at the same time feel excited about his/her twin. Other parents experience this too. Don't be afraid to discuss this'***.

3. Provide emotional support

The relationship staff establish with parents while they are on the ward or in regular contact (in out-patient or primary care settings, for example) can be enormously helpful to the parents. Many parents have told us they really value the empathy and support they received from staff during this time. It is important that the value of talking to parents and providing emotional support to them is recognised. Providing emotional support in healthcare environments is every bit as important as many practical tasks.

In many circumstances staff are the only people, other than the parents themselves, to ever 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 the research study. Parents appreciate staff showing empathy and value seemingly small actions and behaviours that demonstrate compassion and caring.

Demonstrate to parents that you are available and willing to listen to them by asking open questions, such as, **'How are you feeling today?'** and **'What would help you?'**

As parents are likely to visit a surviving premature twin on the ward for several weeks their desire to talk about the death of their other twin is likely to change over time, and even on a day to day basis. Try to be alert to this and to be flexible in your approach to the emotional needs of parents.

You could say **'I'll always be happy to talk about [twin who died's name]. Today might not be a day when you want to talk about [him/her] but we can chat on another day.'**

However, it is important to bear in mind that staff have busy jobs and many responsibilities and cannot function as counsellors or psychologists. Whilst recognising this, staff should be aware of the enormous support they can provide to parents.

Staff sometimes worry about 'saying the wrong thing'. On the whole parents appreciate staff giving them the opportunity to talk. Although it can feel uncomfortable for staff to broach this painful subject, it is generally a good idea to bring the subject of the death of a twin up and ask parents to tell you if they think you are 'getting it about right' or if they don't want to talk at that time. Try to start a conversation with parents about how they feel and get an understanding of what their needs are. You could say **'Is there anything I can do for you?'** or **'What can I do to help you?'**

4. Provide appropriate information

Ensuring parents are provided with accurate information and support, and opportunities to access information and support on an ongoing basis, is important. In the research study parents frequently reported that they appreciated being 'kept in the picture' and informed of what to expect throughout the pregnancy. This gave them a sense of empowerment and of having some control over decisions being made. Staff must work in partnership with parents – this means making joint decisions. In order to facilitate this parents need to be well informed and involved in discussing potential risks and developing care plans. The unique role of the parent in the care of their baby(ies) should be emphasised.

Parents who have lost a twin were, understandably, very anxious about the health of their surviving twin. In situations where they spend a long time visiting a surviving twin on the ward they tend to become very accustomed to the routine of the ward and develop considerable knowledge around some aspects of the medical care being provided. Any change to a care plan can be interpreted as very worrying for parents. Therefore, when a change to the care plan is required, this should be justified and explained very carefully to the parents.

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.

If it is known prior to delivery that one twin has died or is likely to die soon after birth staff should encourage parents to think about what they would like to happen at delivery. Make sure that any preferences parents have are recorded somewhere and passed on at staff handover. It is helpful if any decisions parents make are recorded in their notes so that it is clear to staff involved in the labour. It should be emphasised, of course, that these plans can be changed at any time. Provide parents with as much information as possible about what to expect and plenty of time so that they can make informed choices. If a twin has died in utero, prepare the parents for how the fetus is likely to look at delivery. A list of specific practical issues to consider, and for which parents need to be provided with appropriate information, is provided in Appendix A.

Having provided the parents with as much accurate information as you can about how the fetus is likely to look at delivery you could say '***Have you thought at all about whether you want to see both of your babies together after their birth? Some parents find it comforting to have had at least a short time when their twins were together after they had been born. You don't need to decide now. We can talk about it more later.***

It is important to get the balance right between giving parents all the information they need to make well-informed choices and overloading them with too much information all at once. Try to gauge whether or not parents are taking in and understanding all the information you are giving them. You could simply say '***Have I made that clear?***' Check if they want more information at that time or if they would prefer to get more information later – '***Is that enough for now? Shall we talk more later?***

There will be times, particularly for junior staff, when you are unable to give parents a piece of information that they request. In this situation tell the parents that you will find out from

another member of staff. You could say ***'I'm sorry I don't know the answer to that but I'll find out and come back to you if that's OK'*** and check with a colleague.

Information on accessing services, such as bereavement support, should be available on the unit and all staff should be aware of when it is appropriate to put parents in contact with these services and familiar with the procedure for doing so. Parents sometimes think there is a stigma associated with 'admitting' to needing psychological support provided by the bereavement counselling service. This needs to be handled sensitively.

5. Provide continuity

One of the key research themes was 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, and when families are transferred between wards, hospitals and departments, it is very helpful if all staff ensure that information is communicated effectively. Clearly 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. Be clear about the names of both the surviving twin and the twin who has died.

Another way of giving parents a sense of continuity is to let them know when they are likely to see you again. You could say ***'I'm finishing my shift in 40 minutes and I'm not in tomorrow, but I'll see you on Friday.'***

When meeting parents who have lost a twin introduce yourself and refer to both of the babies by name. For example,

'Hello. I'm <name>. I'm one of the <staff role> on the unit. I was sorry to hear about the death of <Twin A's name> brother/sister, <Twin B's name>. I realise it's a very difficult time for you. Anytime you want to talk about what happened I'd be only too happy to discuss it with you. Just now I'm here to.....'

Some units are fortunate to have a midwife or nurse who has the role of 'twin birth champion'. This person is introduced to parents when a twin pregnancy is confirmed and provides continuity and a familiar face to parents following the death of a twin. The provision of a dedicated twin pregnancy specialist also enables that individual to develop knowledge and expertise in supporting parents to deal with the practical tasks that must be completed after a twin death. In many units it is not possible to have a dedicated twin birth champion. In these situations it is even more important that procedures for ensuring continuity of care are in place.

6. Offer memory making

Generally parents value and find comfort in photographs and mementos of their dead twin and appreciate having a record of both of their twins together. It is a good idea to keep copies of photographs (and any other mementos) as sometimes parents don't want them at the time, but regret not having them later. Other mementos to consider making include footprints and handprints and memory boxes. It might be possible to have joint memory boxes and prints, so that parents have a memento (in addition to photographs) of both twins together. Another idea to consider is giving each twin a small cuddly toy. The toys can be exchanged between twins to give them a sense of each other and after the death of one of the babies the parents can keep the toy as a memento. When both twins are born alive, but one twin dies shortly after delivery, parents particularly cherish memories of both of the babies together while they were both alive. With this in mind it is important to inform parents quickly if the death of one twin is anticipated to allow time for these memories to be made and for them to have the opportunity to see and hold both of their babies at the same time.

You could say 'Many parents find it comforting to have memories of having cuddled their baby and having had both of their twins together. Often parents like to have photos of their babies together to look at in the future and to have prints of their hands and feet. Even if you don't think this is something that you want right now we can take the photos/prints and keep them for you, in case you decide you want them later'.

If it is not possible for the twins to be put together (because there is a risk of infection, for example) explain this to the parents as sensitively as you can.

Try to facilitate parents' wishes wherever possible. You could ask parents if there is anything they want to do in terms of creating mementoes of their twin(s) that they would like to have.

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 (see Appendix A).

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.

You could say ***'Many parents who have lost a twin find it difficult to be on a ward with other twins. Would you prefer your baby to be nursed in a bay where there aren't other twins?'***

Of course, it won't always be possible to avoid placing a surviving twin in a bay with other twins because of the demands on space. In this situation it is best to explain this to the parents and acknowledge that this isn't ideal.

You could say ***'I'm sorry but the only cot we have available is in a bay with a set of twins. I realise that this will be painful for you. I wonder if it would be helpful if I explain your circumstances to the other parents in the bay?'***

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 the discharge from hospital of their surviving twin back into the 'real world' can be a difficult and stressful time. Good communication with and transfer of information to community services at the time of discharge is vitally important.

There are a number of things that staff can do to help to make this transition easier for parents. Suggestions are included in Appendix A.

References

1. Richards J et al 2015 Parental perspectives on the perinatal loss of a co-twin: A qualitative study BMC Pregnancy & Childbirth *in press*
2. Bryan E, Hallett F. *Bereavement. Guidelines for professionals*. London: Multiple Births Foundation;1997.

Resources

- **MBF – The Multiple Birth Foundation** <http://www.multiplebirths.org.uk/>
- **CLIMB – Center for Loss in Multiple Birth** <http://www.climb-support.org/>
- **TAMBA – Twins and Multiple Births Association**
<http://www.tamba.org.uk/>
- **SANDS – Stillbirth and Neonatal Death Society** <https://www.uk-sands.org/>
- **CONI – Care of the Next Infant** <http://www.lullabytrust.org.uk/coni>

Appendix A

Practical issues to consider, issues to discuss with parents and specific help and support that staff can provide are summarised in this appendix. This is intended not to be used as a checklist to go through with parents, but as an *aide-memoire* to help to ensure staff have given parents the opportunity to consider important issues and support with practical arrangements.

When a twin dies before delivery

- Do the parents think they will want to see the dead twin after the birth?
- Do the parents want the dead twin to remain with them for a period of time (if feasible)?
- Do the parents want to have both twins together for a period of time (if feasible)?
- Do the parents want to have a memorial ceremony or funeral?
- Ensure parents know where the body of their twin will be stored in the first few days after delivery

After the death of a twin

- Support with planning and arranging a memorial service or funeral
(Parents often appreciate it if a member of staff from the unit, who knew the baby, attends the funeral)
- Do the parents want to have a post mortem on the dead twin?
(Discuss and provide advice on the need for an autopsy)
- Do the parents want to determine the zygosity of the twins if this wasn't confirmed prior to delivery?
(Discuss the implications of this for the surviving twin)
- Ensure parents have access to bereavement counselling
- Provide advice on registering the births and the death(s)
- Provide advice around making contact with other agencies (e.g. the primary care team; advice around financial support that is available etc.)

When a surviving twin remains in the unit

- Explain to parents that they are likely to come across other twins
- Ask parents about where they would like their twin to be and accommodate their wishes as much as possible

- Avoid caring for the surviving twin in a cot in a bay with other twins if possible
- If a surviving twin has to be cared for in a bay with other twins consider using screens if available to provide privacy
- Be sensitive about putting another baby into the space where a twin has just died and warn parents before they enter the ward when this has had to happen
- If a twin has been moved for any reason let parents know before they come onto the unit
- Avoid moving or scheduling procedures for the surviving twin on the day of the funeral for the twin who has died

When the surviving twin is discharged from hospital

- Ensure parents are given a pre-discharge meeting with a member of staff (consultant or nurse) with whom they feel comfortable to discuss the discharge of their surviving twin one week prior to discharge
- Offer bereavement support to parents and ensure they know how to access this support after leaving the hospital
- Put the parents in touch with a 'buddy group' (if one exists) or with parents who have had a similar experience and can provide support
- Provide parents with contact details for any appropriate local groups, as well as national and international organisations that can provide support and advice.
- Ensure that an information sheet is included in the surviving twin's notes to indicate that they are a twin so that it is obvious to any staff involved in the subsequent care of the surviving twin.
- Arrange a follow-up appointment for the parents to meet with a named consultant from the unit to discuss the reasons for the death of their twin and the results of any autopsy etc.
- Provide reassurance to the parents about the health of the surviving twin (as appropriate)
- The research identified key things as being particularly painful. Examples include returning to the unit for follow-up care and dressing the surviving twin for the first time, if the parents had dressed the dead twin for the memorial service. Be aware of these difficult times for parents and be on hand as much as possible to provide support and prepare parents for them.
- After discharge from hospital, especially for parents whose surviving twin was not preterm and therefore not offered routine follow up, it is recommended that follow-up in the style of that provided for families who are planning a pregnancy after the death

of an infant (CONI: Care of the Next Infant; <http://www.lullabytrust.org.uk/coni?>) should be offered

Appendix B

Illustrative quotes

Quotes from our research study to illustrate each of the points in the guidelines are provided below. Each of the quotes is taken directly from transcripts of interviews undertaken for the research study and the person being quoted (parent or staff member) is indicated in parentheses.

1. Recognise 'twin status'

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

'they [staff] all acknowledged what's happened, and I think that that was really important....nobody ever tried to treat us like parents who'd just had one baby' [Mother]

2. Acknowledge the bereavement

'people say you're lucky to get onewe wanted two, we were having two' [Father]

one of the doctors at the time really quite upset me and she often said to me "at least you've still got one".....that was one of the worst things that anyone could possibly say' [Mother]

'I always felt I mismanaged that situation emotionally for her because for me it was all about the 28 week baby that was alive.....I felt I gave the best practical care but I always felt I hadn't acknowledged [twin's death] in the way that I should... We don't acknowledge the grief, we try and focus on the positive. We should perhaps be dealing with both the elation and the grief at the same time.' [Midwife]

3. Provide emotional support

'Dr X spoke to us on SCBU that morning, saying 'oh you're the guy who's [flown back from X]...I thought now how can you even remember that, you've got so many babies and so much being....but he remembered this grandfather being abroad yesterday' [Grandmother]

'they [staff] weren't allowed to get upset around you....you knew that they were kind of like leaving the room....a comfort that someone around you is upset with you....' [Mother]

4. Provide appropriate information

'So all the way throughwe were totally informed, they didn't try and hide anything.....you have to hear the honest truth but there is a way of putting it' [Mother]

'they took me to the special care unit when I was 24 weeks to show me how a baby that was born early would look' [Interviewer: 'Did that help?'] 'yeah it did, it did so when she came at 26 weeks I already had an idea' [Mother]

'she [midwife] talked us through you know the idea that we could get her baptised if we wanted to, we could see her, we could spend some sort of time with her....so she had told us all the options and then when it came to it on the day, they were really good.....the other nurses.....she must have spoken to[them] and stuff as well so '
[Mother]

'things were bleaker than they said all at once right at the beginning and I think that's definitely what we needed at the time.....they never lied.....' [Mother]

5. Provide continuity

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

'It was, it was really good, we knew [staff member] and trusted her sort of thing and they went off to get her quickly' [Grandmother]

6. Offer memory making

'the nurses did it, they took footprints and handprints; I've still not looked at them – I can't....I'm pleased they did, but I don't know if I'll ever get to the stage that I could look at it' [Mother]

'I have got pictures....it's nice to see that it was both of them together in the incubator'
[Mother]

7. Handle cot occupancy sensitively

'it's a bit heartless putting us on a ward with parents and their twins' [Mother]

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

8. Prepare parents for discharge from hospital

'it was horrible going home when I had to come home that was really hard' [Mother]

'thought it would get better when I got home.... but it actually got a lot worse' [Mother]

'from a follow-up point of view I genuinely feel now that it's difficult to know who to turn to' [Mother]

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This guidance is based on research exploring the views of parents who have experienced the death of a twin and was developed in collaboration with staff working in midwifery and neonatal care. If you have any suggestions on how the guidance can be improved please contact:

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