



Bereavement from a twin pregnancy: Guidelines for health professionals

Introduction

- Staff expressed lack of confidence in dealing with bereaved parents after loss from a twin pregnancy
 - how to instigate a conversation about the loss?
- Parents expect and value emotional work from staff
 - staff often the only people to have ‘known’ the deceased baby
- The way in which staff relate to parents has a major impact on their experience of a difficult and painful time
 - *‘There was one or two who were kind of cold to the counselling part and those aren't the ones you favoured, because they are there to do a job, not for you’ [PO10]*

Overview of training session

1. Recognise twin status
2. Acknowledge the bereavement
3. Provide emotional support
4. Provide appropriate information
5. Provide continuity
6. Offer memory making
7. Handle cot occupancy sensitively on the neonatal unit
8. Prepare parents for discharge from hospital

Recognise twin status

'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]

'..one of the senior nurses...when we were there and he mentioned the deceased twin... and he just came over to me and said 'we know what you've been through...if you ever want to talk about it or you want any, you know what I mean, we are here, we will not ram it down your throat but we are here'' [Mother]

Recognise twin status

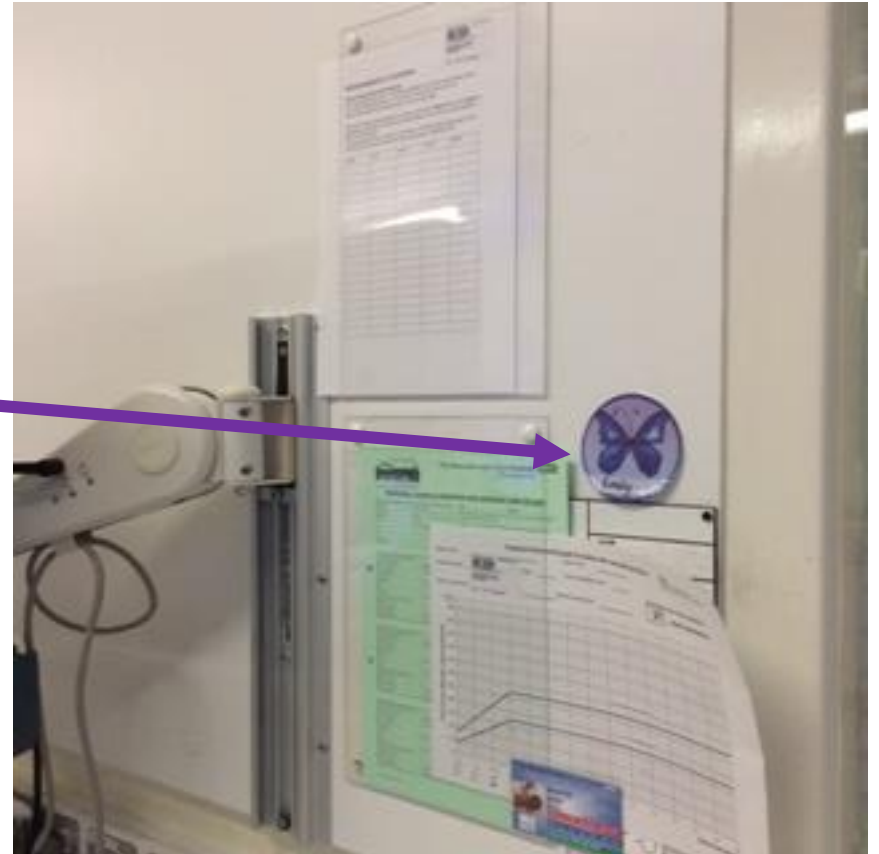
'Nurses would ask 'How was your pregnancy with him?' They forget about him being a twin and everything like that' [Mother]

Recognise twin status

'they forget about him being a twin [Father speaking]' 'it's not just they forget...a lot of them didn't know [Mother]'

'a little blue butterfly.....just put a butterfly on [the cot] then they know he's a twin and then it solves the problem' [Mother]

Butterfly symbol



Acknowledge the bereavement

'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]



Acknowledge the bereavement

'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 demise] 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]



Provide emotional support

'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]

'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]



Provide emotional support

'it was just a bit matter of fact to people' [Mother - referring to the funeral of one of her twins]

'her middle name wasn't put in and it's smudged...'
[Mother – referring to the remembrance book] *'and she just feels upset when she sees it'* [Father]

'one of the nurses that was least conscientious towards other people's feelings kept calling him [surviving twin] by his brother's [demised twin] name' [Mother]



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]

'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]



Provide appropriate information

'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]



Provide appropriate information

'we didn't know where he [demised twin] was in the hospital. I didn't have a clue where he was' [Mother]

'you're 23 weeks into your pregnancy – I was thinking what am I actually going to give birth to, you know, is it going to look like a baby?' [Mother]

'difficult to make decisions [about resuscitation] because I could say "don't go ahead".....they could be born looking and breathing and I could change me mind.....it was just so confusing' [Mother]



Provide continuity

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

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



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]

‘now when I look back I’ll say to [name of partner] “did we ever cuddle [name of demised twin]?”’ [Mother]



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]

'it was really hard to see but you know it has to be done....you can't say you are never putting one in that cot ever again'
[Mother – talking about a new baby being put into the cot where her demised twin had been]



Prepare parents for discharge

'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]



Prepare parents for discharge

- Arrange a pre-discharge meeting with a member of staff (consultant or nurse)
- Offer bereavement support
- Put the parents in touch with a 'buddy group'
- Provide contact details for appropriate groups
- Ensure information sheet included in surviving twin's notes
- Arrange follow-up appointment for parents with named consultant
- Provide reassurance about the health of the surviving twin



Prepare parents for discharge

'it's parents stories [written in book provided in SCU] don't dress it up... they write their story [about losing a baby]...whilst parents are thinking "why am I feeling the way I am?"

...they can read these stories and think "oh right these other parents are going through the same"' [Mother]





Summing up

- Neonatal staff can do a lot to improve the experience for parents who suffer a loss from a twin pregnancy
- There are some small things that can be done to make this experience less painful
- It's important that staff give consideration to their own well-being too – accept your limitations and ask for help and support when you need it



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>



Further information

- These slides were developed out of a project funded by Tiny Lives charity and the Academic Health Sciences Network
- Further updates, copies of the butterfly stickers and parental information leaflets are available www.neonatalresearch.net/parents