



Supporting parents after the death of a baby: Information for practitioners

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Introduction

Stillbirth is the death of a baby after 24 complete weeks of pregnancy, and neonatal death occurs within the first four weeks of life. It is a sad fact that one in every 141 babies dies before, during or shortly after birth in the UK.¹ It is highly likely that practitioners will, at some point in their career, experience the death of a baby or will work with parents who have previously had a baby who died around the time of birth. Many practitioners feel anxious about saying or doing the 'right' things. Of course parents respond in different ways, and in common with most of our work, we need to take our lead from the parents themselves. This guide is intended to provide practitioners with some information about parents' experiences of stillbirth and to share good practice ideas and resources for supporting parents, groups and themselves.

For sale: Baby shoes, never worn.

Six-word novel, attrib. Ernest Hemmingway

What happens at the birth?

If you find out that a baby has died before birth, and the mother has not yet had her baby, you may wonder what they will experience in the hospital. Sometimes parents contact practitioners to talk through their birth options. Each unit is different, and it is a good idea to find out what your hospital offers in terms of care for parents experiencing a stillbirth. Units and individual midwives vary in the quality of care. Some parents will have a better experience than others, but knowing the best practice guidelines can empower them to have more control and a better experience.

Good practice

Find out what facilities your local unit offers. Do they have a special birth room and postnatal bereavement suite? Is there a bereavement midwife? A cold or chilled cot? Do they provide a memory box or other services? (see Useful Charities below)

Sands produce a leaflet '*When a baby dies before labour begins*'² which gives a good overview of what parents can expect. The RCOG Green-top Guideline '*Late Intrauterine Fetal Death and Stillbirth*'³ provides best practice guidance based on available evidence. Some key points from these documents include:

- Women may be encouraged to give birth vaginally to avoid the risks associated with caesarean birth. There is also anecdotal evidence that giving birth vaginally supports the grieving process
- Providing the mother is in good health, there is no urgency to induce labour although the appearance of the baby may deteriorate and the value of post-mortem may be reduced if birth is delayed
- If the mother chooses to be induced, she will be given a combination of oral mifepristone (an abortion medication) and vaginal prostaglandins. Women are often sent home for 24-36 hours after taking the mifepristone, but can stay in hospital if they prefer
- Best practice is to have a special bereavement room on labour ward (so women can access an epidural), away from the sounds of other women giving birth
- Best practice is to have an experienced or specialist bereavement midwife for the birth
- Women report labour as 'physically insufferably hard' more frequently during stillbirth compared to live birth. More women use analgesia
- Women's birth choices can still be respected, and some women labour in water

I took the mum's lead - she wanted to donate milk after birth so I helped her with this.

- Best practice is a private postnatal room if the mother is in good health, where the parents can spend time with their baby if they wish, taking photographs, bathing and dressing. Parents shouldn't be persuaded to see their baby, but supported if they want to
- Some women want to suppress lactation and may be offered medication. This is controversial and can have side effects, but it may be what they want. There are other options available and women may want to talk them through with a breastfeeding counsellor. Other women choose to donate breast milk as a way of making meaning of their experience.

The hospital were amazing. She was allocated a bereavement midwife and they facilitated use of the birthing pool. Although she birthed out of the pool the midwives encouraged her back in to 'catch' her baby, and she said this was really helpful to remember her daughter by. (Sally Parkin)

A woman I supported recently decided to stay with her original plan and had her baby in a pool in the birthing unit. She was extremely happy that she had the birth she wanted. (Philippa Bennett)

I took the mum's lead - she wanted to donate milk after birth so I helped her with this and took meals round for the first week or so (others in the group wanted me to make deliveries). (Sally Parkin)

Parents are often in shock at this point and not able to make quick decisions. Practitioners sometimes have a role in helping them think through their birth choices, including encouraging them to think about their options for making memories with their baby. The Sands leaflet 'Saying goodbye to your baby'⁴ can be very useful in this.

Contacting the parents

Sometimes the parents contact the practitioner directly to tell them their baby has died. If the contact is via email, it is best to respond by email. You may want to offer support via telephone or a meeting. Sometimes parents won't take you up on this offer and you may have no further contact with them. If you hear the news indirectly through another member of a group, or someone else, it is usually appropriate to send an email or a sympathy card, again offering further contact if appropriate. It is really important you decide personally whether you are able to give further support beyond an email or a card. For a number of reasons you may not feel able to speak to the parents directly, either on the phone or face to face. Even if you are keen to do this, take some time to examine how you feel. It may also be a good idea to speak to a member of the NCT Crisis Team, or an experienced colleague first (see 'Getting support for yourself').

Good practice – Things to include in an email:

- Saying you are sorry their baby has died
- Offer to contact the branch and head office to stop correspondence. Some parents don't want all contact to stop suddenly as this can feel worse
- Provide the link to the Baby Mailing Preference Service <http://www.mpsonline.org.uk/bmpsrf> so they can stop receiving baby related mailing
- Include one or two links to useful charities or resources, but don't overwhelm them
- Ask if they would like you to contact the rest of their antenatal group
- Offer contact via telephone or a visit if you feel you would like to.

Supporting other members of a group

If you have been working with a group of parents and one parent or couple experience bereavement, you may have a significant role to play in communicating with, and supporting, the rest of the group. If the couple let you know their baby has died, you should ask if they would like you to contact the group and let them know. This can be difficult to do as they will either be expecting their babies imminently, or have recently had them. If the course hasn't yet finished, you can do this face-to-face, or contact each couple individually by telephone or email, whichever you feel is more appropriate for you and the parents.

Good practice – Breaking the news

- Tell other parents at the beginning of the session
- Ask the group whether they would like to continue the session and if they do, suggest a break before continuing
- Don't be afraid of showing an appropriate level of emotion but be aware that parents may not respond emotionally. This is quite normal
- If phoning, it is better to do so in the evening when the mother is less likely to be by herself
- Give parents the time to express their feelings and ask any questions
- Some practitioners prefer to use email to give parents time to process the information and respond if they choose to
- Follow up the phone calls or emails with a group email. You could offer a meeting if they want one.

I received an email at around 9pm, with the rest of the group copied in, to say that the couple's baby had died. I felt like I needed to get in contact with the others immediately because I had no idea how or when they would receive the news. Some had read the email and were distressed and some hadn't, so I had to break it to them which was awful. One couple had literally just walked in the door from the hospital having had their baby.
(Sam Havis)

Who else to inform

- Let your Practice Support Administrator (PSA) know as soon as possible
- If you're an antenatal practitioner and the group haven't had the breastfeeding class yet, let the breastfeeding counsellor know as soon as possible.

Meeting with the parents

If you decide you would like to offer a face-to-face meeting, and the parents take you up on your offer to meet, it can be daunting to know what to say or what not to say. Even if we have some experience with baby loss, no two people or circumstances are the same. We must use our empathy, active listening skills and take the parents' lead. Parents and practitioners have shared the following key points, which may help you:

- Remember there isn't anything you can say that will make it better
- Use active listening skills – open questions, attentive body language, allow silence
- Parents often appreciate the chance to talk about their baby and the birth. Don't be afraid to ask the normal questions, eg 'who do they look like?'
- If the partner is there, ask how they are too. Partners' feelings often get ignored. This is also true for the wider family including grandparents
- Use the baby's name and acknowledge it as a real person
- Ask if they would like to share any photos with you. Some parents may not want to show you, but many do. Be prepared, the photos might be quite graphic and can be shocking. Hold the photo mindfully – you are holding their baby
- Empathise with parents' emotions – these can include anger and blame. You don't need to try to respond, just listen and accept it as a part of the grief process
- Don't empathise with your own experiences of other kinds of loss, eg parents/grandparents. The loss of a baby is a unique, often isolating experience with very different consequences and impacts
- It is okay to be emotional yourself. Parents appreciate the fact that their loss affects others outside of the family.

We must use our empathy, active listening skills and take the parents' lead.

I went to visit a couple booked on my class who had experienced a previous stillbirth. I asked to see a photo of their baby. The mum started to cry and went to get the picture from her bedside. I asked if she was OK and she said, "It's the last thing I see before I got to sleep and the first thing I look at when I wake, but you're the first person who's ever asked to see it. Even my best friend hasn't asked." (Anne Fawcett)

The reunion

Be parent-centred about telling bereaved parents about the reunion and letting them choose whether to come. Don't assume they won't; some will come. I remember 19 years ago having a reunion group photo of seven couples and their babies and one couple holding a framed photo of the baby they lost. It was very powerful. They didn't decide to come until the last minute and were the last to leave. I encourage bereaved parents to do whatever will meet their needs, including leaving half way through if necessary.

(Helen Ashton)

Further contact

There is no obligation for practitioners to provide support to bereaved parents, but many practitioners choose to because of their unique role in the experience of the parents they have worked with.

Sometimes this support and contact can become an enduring relationship or develop into a friendship. It is entirely up to your judgement as to how much contact you choose to have. Some examples of the ways practitioners have gone forward with in supporting parents include:

- Attending the baby's funeral
- Support with expressing and donating milk if they have chosen to do this
- Sending a card on significant anniversaries, eg the baby's birthday and/or day of death
- Supporting them through a new pregnancy

It is a tribute to the skill of NCT practitioners that parents often return to the same antenatal practitioner to attend another set of classes. This can be an emotional and challenging experience, but very healing for the parents and the practitioner.

A couple have just started on my course, 18 months after they attended the first time and their little girl was stillborn. They specifically asked to be on my course – which is very flattering – as they said they got so much out of it last time. I'm following their lead; they will tell the rest of the group when/if it feels comfortable for them. I'm nervous, especially about covering induction as they are being induced early. At the first antenatal class they arrived early, and we hugged and cried a bit. I found it difficult to make eye contact with them, but that will get better. (Helen Darlaston)

Supporting others through their shock and grief can take an emotional toll too.

Working with previously bereaved parents

If we find out in advance that we will be working with a couple or mother who has previously experienced the death of their baby, there are certain things we can do to accommodate their particular needs. It might be useful to offer a telephone call or meeting in advance. Knowing some of the circumstances and their experience may be useful but is not essential.

Some parents or mothers attending courses have strong feelings about whether they want to inform the rest of the group about their experience or not. We must respect this and take their lead, but be aware and sensitive to the needs of the rest of the group, and the couple's or mother's relationships within the group.

It is important to remember that sometimes people don't share in advance that they have been bereaved. At any point in our work we should be conscious of the fact that this may not be the parents' first pregnancy or experience of birth and they may already consider themselves to be parents. Certain information or language can trigger strong emotions through no fault of the facilitator. Use empathy and offer a chance to talk privately if appropriate.

Getting support for yourself

It is important to acknowledge the impact that parents' bereavement can have on yourself. The sudden death of a baby can bring feelings of shock and grief, and if you have ever experienced the loss of a baby yourself it can bring up painful emotions. Supporting others through their shock and grief can take an emotional toll too. It is very important you know exactly where you can go for support in this situation.

Crisis support

This is an urgent, short-term support service for practitioners who are experiencing very challenging circumstances in their practice such as the death of a baby. You will receive support from an experienced practitioner (a tutor, a supervisor or a mentor) to help you cope. This service is to enable you to receive short-term support (around an hour) and you will be signposted to other sources of support if you require ongoing help.

Email crisissupport@nct.org.uk with a request for support, brief details and your preferred method of contact, with relevant numbers etc; an available crisis supporter will be found as soon as possible and will contact you to arrange a time to speak as soon as practicable. This address will be intermittently monitored during weekends and bank holidays. This means that the response may not be an immediate one, but is usually within 24 hours.

Local support

Your local colleagues and PSA can be a useful and helpful source of support. If you are not sure who you could talk to, your PSA should be able to signpost you to others at NCT who can help.

Online peer support

There are Yahoo and Facebook groups run by and for practitioners. A practitioner can access immediate virtual support from colleagues. Please bear in mind that these groups – whilst usually ‘closed’ – are not officially run by NCT and practitioners should be careful that they don’t post anything that could identify clients, as we cannot guarantee that they are secure. The practitioner Facebook group <https://www.facebook.com/groups/NCTPractitioners/> and Yahoo group <https://uk.groups.yahoo.com/neo/groups/NCTPractitioners/info> are moderated and posting to either group is likely to elicit a swift response.

Coordinator support

Your specialism coordinator is also available to support you. For contact details see

<https://babble.nct.org.uk/info-resources/education/nct-college-whos-who>. You can also email practitioners@nct.org.uk and have your email forwarded to the relevant coordinator.

Useful charities

Sands Stillbirth and neonatal death charity <https://www.sands.org.uk>

BLISS - for babies born premature or sick <https://www.bliss.org.uk/>

Children of Jannah - support for bereaved Muslim parents
<http://childrenofjannah.com/>

Child Bereavement UK - information and resources on baby death
<http://childbereavementuk.org/>

Cherished Gowns - clothing for babies’ funerals with no charge
<http://www.cherishedgowns.org.uk/>

Remember My Baby - professional photography, no charge
<http://www.remembermybaby.org.uk/>

Useful resources

Best Beginnings – Small Wonders Bereavement – a film looking at baby loss when babies are sick or premature <http://sw11.bestbeginnings.org.uk/>

BLISS pages looking at critical care and palliative care, as well as bereavement
<https://www.bliss.org.uk/Pages/Category/coping-with-loss>

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