perspective

NCT’s journal on preparing parents for birth and early parenthood

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supporting parents through stillbirth

The June 2017 issue of Perspective focuses mainly on stillbirth. Sadly, although involving only a minority of pregnancies, stillbirth and neonatal deaths are devastating events for parents and families.

Practitioners may see parents experience a stillbirth during their antenatal course, or they may have bereaved parents planning to attend their classes. We look at the impact of stillbirth on parents, and the support that practitioners can provide, as well as taking care of their own needs. We feature tips on how practitioners can discuss stillbirth with parents, and initiatives to reduce stillbirth risk and promote safer pregnancies.

New research is making it a priority to listen to the views of parents for the improvement of bereavement care.

We also cover examples of antenatal classes designed especially for parents expecting another baby after a stillbirth, or following a previously traumatic birth. These are providing an important space in which parents can share their experiences and receive the support they need. Plus a look at the uncertainty around the effects of endocrine disrupting chemicals.

Do get in touch if you would like to share your experiences.

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Anxiety levels in the room can be very high. Some are very anxious and tearful and emotional. Others are very positive.

Rachel Cox

By Julie Clayton

Mums who become pregnant again after losing a baby have very different needs, as midwife Rachel Cox found when she developed a special antenatal class, ‘Pregnant Again’

Not a normal class

The idea of running an antenatal class especially for mums who have had baby loss came from the Bristol branch of Sands who were supporting mums but wanted to combine this with antenatal education. It’s developed over nine years and is definitely not a normal antenatal class!

When we started I had a doll, a pelvis and a knitted boob. I used these a couple of times and was all ready with my midwifery input, but I quickly realised that these were not needed because a lot of the session was talking through the practicalities of what was going to happen. There were stages of pregnancy that some women had not gone through, such as the 20-week scan, and later growth scans. And 36 weeks was alien to many, so they didn’t know how they were going to feel and needed a lot of support.
We see an average of three to four couples; some bring their mums or a close friend too. We get a lot of people who have done a support group where they have been able to talk about their dead baby, but then when they are pregnant again they felt awkward going in with their bump.

**High anxiety levels**

Anxiety levels in the room can be very high. Some are very anxious and tearful and emotional. Others are very positive. It just depends on personality. They are taking their pregnancy a day at a time, some days good, some not so. They wake up every morning waiting for their baby’s kick, that next scan. They tick the days off, and the milestones, the 20-week scans, 24-week check – my baby died then. It’s different for each person. One mum recently, even at six weeks post-delivery, was so scared that someone was going to take the baby away.

I’m there to provide antenatal education and support but I also have befrienders who have lost a baby – who have gone through the sessions and can draw on their experiences.

As a practitioner, I have learnt so much. We run a block of three monthly sessions split very loosely into antenatal, intrapartum and labour, and postnatal. But it’s very much driven around what the women and families want to hear. They can be at very different stages of gestation, so in one might be at 27 weeks, another at 15 weeks, and another almost at term, all in the same session.

**What to expect**

At the first session everyone tells their stories, as much or as little as they want to, about how they became a bereaved parent. As a midwife I can gauge what stage of loss it was – some are really early, others may have been at term. So everyone appreciates where everyone else is coming from and their aims, such as whether they want a vaginal birth, induced labour, or an elective caesarean.

We talk about scans, blood tests, consultant-led care, and relationships with consultants and community midwives. A lot of women who come in opt for an elective caesarean birth, which is offered automatically if a woman has had a loss neonatally or stillbirth. Some will opt to birth naturally, mostly with induction. And one mum recently had a home birth. Few women who have had previous losses will go to term. They prefer to be induced at 37 to 38 weeks just because of their anxiety. They may have had a loss previously at 39 weeks and want that baby out sooner.

We also prepare mums for what other people are going to say. Friends and family might say “That’s great you can have another baby”, or “I’m so glad you’re pregnant again’ or “It’ll be fine” – because they think that’s what you want to hear.

The session on intrapartum care and labour mainly covers the process of induction and caesarean birth. Unlike conventional antenatal classes, pain relief and breathing technique rarely get mentioned because they’re not expecting to go through that and it’s not what they’re interested in. As a midwife, it’s difficult for me not to talk about active birth.
Going home with a baby: unimaginable

I always warn them that the most difficult session is the postnatal session, because the thought of going home from the hospital with a live baby just hasn’t entered their heads. There’s a slight hope but they don’t want to think about it, because last time they left the hospital without their baby. So when I talk about postnatal care and breastfeeding they’ve almost shut off and say very little as I talk about it.

I focus on the practicalities of postnatal care: how long you stay in hospital, having a catheter in for a day after a caesarean, feeling tired after a blood loss. We talk about the emotional aspects – that the baby may look like the one they lost and how they might feel about that. Or how they might feel being in a postnatal ward with other mums who ask, “Is this your first baby?” Will they say their first baby died, or do they not acknowledge it?

Taking back control

I plan loosely what to talk about but I empower them to ask by saying, “This is your class – come to me with what you want to know”. We talk about how it feels to go back to the antenatal clinic, where some mothers find out their baby has died through a scan. Even if they have a Sands ‘tear drop’ sticker on the front of their maternity notes to show they’ve had a baby loss, some staff might not see it and might call them up to the same scan room that they went into before. They may be absolutely terrified and feel isolated because no one's acknowledged that. I try to empower women to use their voice, be an advocate for their own pregnancy, and to say, “I’m really nervous”, and to talk to their consultant.

Birth plans are always difficult to discuss. They’ve usually already made a firm decision about the birth they want. I try to give them an idea of the alternatives and one or two might change their minds. They want to do what’s safe for their baby but we aim to make them active in their own decisions and not just to feel that they are being led.

We focus on practical things to help them have some control, and what they might or might not want, such as continuous monitoring during labour, music in the theatre, and skin-to-skin with the baby after the birth. We’re trying to empower them to claim their pregnancy back for themselves.

Taking the fear out of the delivery suite

At the end of the sessions I always offer a private tour of the hospital because a lot of parents haven’t stepped into the delivery suite since their baby died, and going into hospital is a very anxious time. I show them the theatre and delivery room so that when they come back they remember it. For the dads too there are lots of memories. The tours have been really positive for a lot of people.

Glowing feedback

Parents attending ‘Pregnant again’ often form friendships and get together outside the class. It’s lovely when we hear they’ve had their baby, or they post onto the Facebook group to congratulate each other or recommend the class to others saying things like, “I couldn’t have got through it without the classes.”
Reflection points on talking about stillbirth in antenatal classes:

- Don’t be afraid to talk about stillbirth in your course. If we never mention stillbirth, and it happens to a client, is it worse that no one ever talked of it? To not talk about stillbirth seldom helps parents, and could make them feel worse if it happens to them.
- Reflect on why you do or don’t mention it in your courses. Whose needs are being met?
- Be real about the discomfort this can cause some people. Acknowledge it’s not easy to talk about.
- Explain why it happens and quote statistics too to keep the idea of risk in proportion.
- Would you cover stillbirth in your course, and how?
- Respond to the parents’ agenda: you may wish to discuss stillbirth as part of another theme, or take the opportunity if someone else mentions stillbirth.
- There’s no right way to cover stillbirth. It has to feel right for you as a practitioner.

(Helen Ashton, NCT Excellent Practitioner and antenatal teacher)

Practice tips

What happens if there are bereaved parents on your course?

Some practitioners won’t tell the rest of the group about a stillbirth until all have had their babies. Other antenatal teachers will tell them at the time they hear the news.

- Find out and respect what it is the bereaved parents want.
- Remember the core conditions of empathy, realness and having a non-judgmental approach.
- Telling the rest of the group before their births may not necessarily worry them more as they may well fear stillbirth anyway.
- Talking about it openly can help, and the rest of the group may well support the bereaved parents, depending on how well they have bonded and their personalities.
- Adapt your session to accommodate the news and the group’s reaction to it.
- Keep useful information in mind for if and when the bereaved parents disclose this information to their group, in order to facilitate the rest of the group’s reactions and the remainder of the session. This may include local and national sources of support.
- Acknowledge how the bereaved parents are feeling this time around: they are in a group of first-time parents, yet they are parents already but don’t have a child. They might cry in your sessions, or go out unexpectedly. You need to manage this sensitively for them and rest
of group. Have tissues ready. Allow them to opt out of any activity, or conversely, to tell their experience. I’ve had both happen with the same bereaved client!

- Refer to the first lost baby by name during course if couple have disclosed this and are happy with this.
- Acknowledge the differing but equally important fears and needs of the birth partner, as well as the bereaved parents and the rest of the group on your course.

*(Helen Ashton, NCT Excellent Practitioner and antenatal teacher)*
Supporting parents through stillbirth

Linda Gustard, Divisional Head of Midwifery/Gynaecological Nursing, Chesterfield Royal Hospital, describes her experience of providing care for parents and their stillborn babies – and one mother’s unexpected inspiration

In many ways, loss in childbearing is unique. This uniqueness is due to the awful contrast between the sorrow of death and the joy of the birth of a new life. There is also the cruel paradox of the juxtaposition of birth and death. We expect these events to be separated by a lifetime and the experience becomes incomprehensible when they occur at the same time.

Mothers of stillborn babies will often experience feelings of guilt, and believe that something they did or didn’t do contributed to the baby’s death. Equally, many parents will feel that the death of their baby was not an inevitable tragedy, and that opportunities to prevent their baby’s death were missed.

Being sensitive to how parents feel

The health professionals who provide care to parents during the birth of their stillborn baby need to be sensitive to the complex emotional roller coaster of grief, guilt, anger and blame that parents will experience. The care, support
and information that parents receive will influence how they cope with, and recover from, their loss.

This process starts with how parents are told that their baby has died. The majority of stillbirths occur during pregnancy, before the onset of labour.

A period of reduced or absent movements typically precedes the baby’s death, and this is usually the reason the mother makes contact with her community midwife, or the maternity unit where she is booked for care, and is asked to come in for a check-up.

The usual procedure involves a midwife undertaking a routine examination, including locating the baby’s heart with a Pinard stethoscope (which amplifies sound for the listener) and/or a Doppler ultrasound monitor. The first midwife can spend a variable length of time trying to locate the baby’s heart before asking a more senior colleague to try. Medical staff may then become involved and an ultrasound examination performed to confirm the diagnosis.

For parents it is an agonising wait to know whether their baby is alive or not, and they will never forget how this was conveyed to them by staff.

Openness and honesty

Staff should be honest from the outset. The admitting midwife should be careful and thorough but should not spend a protracted time trying to locate the baby’s heart. There is nothing worse than listening to minutes of whooshing and crackling from a Doppler monitor in search of a baby’s heartbeat.

Before enlisting a colleague, the midwife should explain that she cannot locate the baby’s heart and what that could mean. Staff can find this really difficult; they could be wrong and cause unnecessary distress to parents, or if they say the wrong thing, they could get into trouble. However, in my experience, parents want and need staff to be honest at all stages, to explain what is happening, and help them to prepare for the worst.

For most stillbirths in pregnancy, women will be recommended to have their labour induced, unless this is contraindicated. Many women cannot contemplate going through labour to give birth to a stillborn baby. Staff need to be skilled and sensitive in explaining to the mother that a vaginal birth is better for her physical recovery and longer term health, and that the process of ‘giving birth’ to her baby affirms that she is a mother.

A stillbirth that occurs during labour is likely to be caused by a catastrophic clinical event, and will almost certainly trigger a serious incident investigation within the organisation involved. In this situation, it is imperative that staff are open and honest with parents about what could have caused their baby to die.

Care in labour is both for the mother and her baby. The physical care needs for a woman with a live or stillborn baby are very similar. However, the psychological care needs are poles apart. When the baby is alive, the priority for staff is to monitor the baby’s heart rate, assess the baby’s wellbeing, and detect signs that the baby may be distressed. For a woman with a stillborn baby there is no heart rate to monitor, but there is still a baby to care and prepare for.
Connecting parents with their babies

The midwife providing care should talk to the parents about the creation of memories of their baby. These include taking photographs, hand and footprint, cutting a lock of hair, naming the baby and bathing and dressing the baby. Parents should be encouraged to perform cultural birth and death rituals such as baptism.

Midwives also face the quandary of how much to encourage parents to have contact with the baby, which can be particularly difficult if the baby’s skin shows signs of deterioration when born. It is really important that the midwife prepares parents for their baby’s appearance at birth.

As for a mother expecting a live baby, the midwife should ask the mother if she would like to have the baby placed onto her chest when born, for skin-to-skin contact. There is no reason why the father cannot cut the cord. These actions enable parents to have the contact with their baby in the way that they would if the baby was alive.

Most maternity units have facilities specifically for parents who have had a stillbirth, which enables parents to stay together with their baby for as long as they can while in hospital. Other family members and siblings can also have unrestricted visiting.

Parents should be encouraged and supported to make their own funeral arrangements. The funeral serves a multiplicity of purposes, including a demonstration of support by others, as well as establishing the reality of the loss. Taking responsibility for these arrangements, and being able to influence the service for their baby, is an important milestone in the grieving process.

Parents may be advised that the baby should have a post mortem examination. This raises difficult issues for parents who may consider that their baby has suffered enough already, and they should never feel pressurised into giving consent.

The parents of a stillborn baby will leave hospital armed with information related to physical and psychological care, practical issues such as registering the birth, and support services that are available both nationally and in their locality. Parents may assume that the answers to every question are contained within the information somewhere.

Life after stillbirth

3rd October 2014. Our worlds crumbled and were never to be the same again. Our little boy, Joel, was born sleeping aged 40 weeks exactly. His due date. His birth date. His death date.

I didn’t want to leave the hospital. I had received wonderful care and I was comfortable with my new found grief residing in that hospital room. Although Joel had been taken to the mortuary I still felt him close by. I didn’t have to worry
Sarah’s story

At Chesterfield, we regularly review and update the information provided to parents in relation to clinical procedures and care pathways, including care following stillbirth, based on current evidence-based recommendations. The information is written by healthcare professionals and is very factual, with specific advice for specific issues. I had always thought this was adequate… How wrong I was.

Early in 2015, I was contacted by Sarah, whose son, Joel, was stillborn in October 2014. Joel had died on his due date and was born at the Chesterfield Royal Hospital birth centre. In her email to me Sarah explained that the care she received during her induced labour was really good and how grateful she was. She had gone home with an armful of our information and was sure the answers she needed would be contained within this pile of knowledge. However, Sarah later told me that the information she received that day didn’t even cover the weeks after the funeral. This led Sarah to an idea of what she wanted to do, and so we arranged to meet.

Sarah wanted to use her experience to help other parents. I listened to her story and together we worked on the idea of creating a book.

Sarah’s book is titled ‘Life After Stillbirth: Your New Normal’, and is based around Sarah’s story entwined with other parents’ experiences. The book is divided into various sections for parents to read when they feel it would be most beneficial.

When Sarah was undertaking research for the book she shared her story on social media and was overwhelmed with responses from parents all over the world who had experienced stillbirth and had unmet needs.
The book captures parents’ experiences of returning to work, the anniversary of the baby’s death, remembering the baby, family and friendships, negative emotions, other pregnant women and the foolish things that people can say. At Chesterfield we give a copy of Sarah’s book to parents who have had a stillbirth.

Sarah now has a rainbow baby (a child born after a loss), but she could not enjoy a single day of her new pregnancy because of knowing – and having experienced - what could go wrong. Sarah is currently writing another book for parents, ‘Your Rainbow Baby’.
Supporting parents after the death of a baby: Information for practitioners

By Sam Havis, NCT Service Support and Improvement Team

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. 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.
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’ which gives a good overview of what parents can expect. The RCOG Green-top Guideline ‘Late Intrauterine Fetal Death and Stillbirth’ 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
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.

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’ 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’).

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)
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.

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/bmpra](http://www.mpsonline.org.uk/bmpra) 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.

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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.
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)

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 chose 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)
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
References

1. ONS data compiled from three sources:


Supporting parents after trauma

By Eleanor Molloy
NCT Breastfeeding Counsellor (Coventry Branch)

Hooked, dry and trying to push,
A bedframe, a glance, a finger’s cut,
As hands gripped mine,
Tears drenched salted and bottomless,
As each hour passed another person came to me,
With new faces overcrowding me-
I neglected to focus on yours,
I lost control in that space.

extract from 'Finding You', a poem by Madeleine Richards
http://www.birthtraumatrust.org/poem-finding-you/

The way in which a woman experiences her labour and birth, and the care she receives, can have an enormous and ongoing impact on how she feels and thinks of herself as a mother, and her ability to parent her infant(s) effectively.1 Across the UK, up to 33% of women giving birth each year may experience their births as traumatic.2 Between 5-10% of these women may go on to develop complex mental health issues such as post-traumatic stress...
disorder (PTSD). Recent work indicates a prevalence rate of between 3-4% of PTSD symptoms in women who have suffered traumatic birth. Common experiences may include flashbacks when being around or near the place of birth, as well as nightmares and anxiety around decision making and baby’s and mother’s health.

A traumatic birth experience can potentially have an impact not only on a mother’s mental health but also on bonding between mother and baby, on the breastfeeding relationship between mother and child, and on other close relationships.

As a part of my MSc in Child Health, I undertook a study exploring the experiences of women seeking support for PTSD following birth trauma. I found that often, women who suffer from issues such as PTSD are not always able to seek support within a defined time frame. Some women find that it is months after the event before they are able to begin to talk about their feelings and experiences. Some have lost trust in their health care professionals due to their birth experiences, and may need support in being able to talk to the people who can help them start on the road to recovery. Mothers fear being judged for not enjoying parenthood in the way they feel they should; and others are angry and scared that if they admit having struggled to bond with their infant they may be judged about their fitness to parent.

NCT Coventry Branch has been running a ‘Birth Choices, after caesarean or traumatic birth’ peer support group since 2007. The group was set up by one of the branch antenatal teachers, Rachel Bridgeman, during her training, to offer a place for information and discussion around next steps and options when looking at subsequent births after a caesarean birth. Rachel’s own first birth experience led her to seek the support of our local supervisor of midwives in her plans for a home birth after a caesarean. I too was supported by Rachel and the group in my wishes for a hospital vaginal birth after a caesarean (VBAC), without continuous monitoring. The group was instrumental in allowing me access to information about choices, options, and details about risk and the perception of risk.

In setting up the group, Rachel sought the support of NCT Coventry branch, which funded the venue, and the local maternity services. The group was often well attended by mothers and supported by midwives. At the time, Coventry had no specific VBAC clinic, but one did exist by the time I had my third baby in 2013. As time went on, the group became embedded in the branch offering to local parents, and its scope widened organically to offer support and information to families who had experienced a traumatic birth — with or without interventions such as forceps or caesarean birth. The group was supported not just by the supervisor of midwives, but also by the head of midwifery, and the postnatal ward manager who also arranged a route for women who wished for a birth debrief before the local hospital set up its Listening Clinic in 2016.

I found the group a huge source of support when looking at information around home birth for my third child in 2013. Due to funding pressures the group now met at Rachel’s home. Rachel’s day job had become full time and she was looking for volunteers to continue to facilitate the group. I offered
to job-share the role together with another mum who had participated in the
group, starting in 2014. This role, together with my interactions with women
as a breastfeeding counsellor (BFC) and as a peer supporter in the Coventry
Council Infant Feeding Team, led me to think about setting up a group for
women who were struggling emotionally after birth. I discussed this with
our branch chair, the postnatal ward manager, and a clinical psychologist on
the perinatal team; I also asked local parents for their thoughts and feelings
about such a group. The response was overwhelmingly positive. I secured a
grant via a local church group to cover the cost of room hire, and launched
the Coventry NCT Perinatal Mental Well Being Group (PMWB) in April 2016.
As a non-statutory service we have the flexibility of not needing to restrict
the ages of children; most women who attend have children up to the age of
two years. As group facilitator, I predominantly talk to women on a one-to-
one basis depending on need, or facilitate whole group discussions around
pertinent topics such as medication (fear about starting medication or
increasing dosage) or talking therapies. We have had an NCT yoga teacher
lead a session, and enjoyed activities such as adult colouring too. We have
had women attending before and after stays in Mother and Baby Units, or
following referral from other sources of support. Some may have heard about
the group via social media or a friend. All attendees are given a printout
explaining that the group is run voluntarily, and that there is an expectation of
confidentiality. We also state that safeguarding principles will be adhered to,
and remind participants to seek professional support for any ongoing issues,
such as from their health visitor, GP or perinatal team; we never offer
medical advice.

The PMWB group was set up just prior to a call for interest from the NCT
Parents in Mind (PIM) pilot programme for training peer supporters for
women with perinatal mental health issues. NCT’s Coventry and Warwick
Central Branches became the first pilot area for PIM, and the current PMWB
group will soon be run by the first cohort of newly trained peer supporters.
This is an exciting time for all concerned and provides an opportunity to
evaluate the group’s impact on women’s mental health.

For women with issues beyond thinking about birth, the PMWB group offers
social support in a place where women do not fear being judged for their
feelings around parenting or their need for medication or therapy. Both
the PMWB and the Birth Choices groups have varying attendance levels of
between one and eight women each session. Some women bring a friend in
order to help them engage with the group, or have had conversations with
the group facilitator prior to attending.

While ‘homeless’ over the past few years, the Birth Choices group now meets
monthly at one of the local Children’s Centres, with regular attendance by
one of the Supervisors of Midwives. We provide tea, coffee and biscuits and
offer books for women to borrow, along with back issues of various midwifery
journals (MIDIRS Midwifery Digest usually). A big part of the group’s role is to
offer a space for women to come and talk about their birth without feeling
they will be told to ‘get over it’. The group is open to women no matter when
they gave birth. Some women come because they want to talk to others but
are unlikely to be having more children; others come because they unsure
and want to hear experiences of women who have birthed after a traumatic
Birth. Some of the women who attend want to think about ideas for a planned caesarean birth. Women are encouraged to talk to their consultant/midwife/supervisor of midwives about their individual wishes and options. We also encourage women to talk to their health visitor or GP about referrals to the local perinatal psychology team, and to think about attending the PMWB group.

The rooms are warm, carpeted, and not huge – we can confirm that echoing around a church hall with only three people inside isn’t conducive to a warm welcome! Parents gain confidence in their abilities to parent, even with ongoing issues, as they see others who have done, and are doing, the same. They also gain from creating a social support network, where they may have been isolated by their feelings about their birth previously.

**Tips for practitioners**

We know that women may suffer from ongoing mental health issues that are exacerbated or triggered after a birth that is experienced as traumatic. Some of these women may feel unable to seek support in the early weeks and months postpartum.

- **Think** about the language that is used, many women fear being told that because baby is OK, the birth experience is unimportant. This can cause women who perceive that their needs and feelings are seen as irrelevant to shut down rather than seek support.
- **Think** too about local support services; perinatal mental health teams, health visitors and midwives who are mental health specialists or champions.
- Are there local third sector offerings that can provide more intensive support, eg. Coventry MIND Charity also provides [Mums in Mind](https://www.cwmind.org.uk/mums-in-mind), a six-week peer support course for women who are feeling socially isolated.

Knowing where to refer parents to can help with improving confidence when asking parents how they are feeling about parenting and their birth. All groups of practitioners see parents at various stages postnatally, whether attending a reunion, volunteering at a Nearly New Sale or breastfeeding drop-in, or running an Early Days or Introducing Solids course. Parents who present as being overly anxious about certain areas of child care may just need extra information, or they may just need the right person to ask the right question.

Practitioners interested in running similar groups need to think about space and boundaries – in terms of not only emotional support offered to women who may be retelling difficult stories, but also physical space for storage of resources, and an appropriate location. We have struggled with trying to balance being welcoming to partners and the need to limit those attending due to the confidential and (often) sensitive nature of group discussions. However, support for birth partners after traumatic birth is equally important, if harder to find.15

Parents gain confidence in their ability to parent, even with ongoing issues, as they see others who have done, and are doing, the same.
NCT Parents in Mind

The Department of Health-funded NCT Parents in Mind pilot aims to develop, deliver and evaluate safe and effective peer support for women experiencing perinatal mental health issues. In Coventry and central Warwickshire there are currently seven trained peer volunteers delivering support weekly in Coventry, Leamington and Warwick. Another ten volunteers are in the midst of training and will be joining the peer supporters from September thanks to local funding from Warwickshire Smart Start. For women wanting to refer into the service please contact Sarah on 0788 597 5261 or email parentsinmind.wc@nct.org.uk. Parents in Mind is also operating in Widnes and Runcorn, and the London borough of Newham. Trained volunteers start delivering support in the North West at the end of June and volunteer recruitment is just starting in Newham.

The key elements of the project are to test and understand:

– What safe support means. For example, adequate training, appropriate support for volunteers when supporting others, safeguarding all involved in the service.

– The impact of peer support for women experiencing mental health difficulties in pregnancy and early parenthood on their mental health, feelings of isolation, confidence to seek support, confidence as a parent, etc.

Through a thorough evaluation process in conjunction with City University, we can answer these questions and hopefully support more women in more areas in the longer term.

Progress of the project is being shared via the blog [https://parentsinmind.wordpress.com/] website [http://www.nct.org.uk/professional/parents-in-mind] and Facebook page [https://www.facebook.com/nctparentsinmind/].

References

Online support:
Birth Trauma Association: www.birthtraumaassociation.org.uk
Birth Trauma Trust: www.birthtraumatrust.org
Have You Seen That Girl: www.haveyouseenthatgirl.com/
Unfold Your Wings: http://www.unfoldyourwings.co.uk/

Twitter:
Monday nights 8-9pm live tweet chat #birthtraumachat
Weekly discussion/peer support facilitated by Birth Trauma Trust/
Maternity Matters
Monday nights 8-9pm live tweet chat #dadsmhhour

Peer support via Twitter:
#pndchat is monitored throughout the day for women/families seeking support set up by @pndRosie
To get involved with learning more and having discussions around maternity services in general, and perinatal mental health, you can join groups on Facebook:
MatExp (also on Twitter #matexp)
Perinatal Mental Health Network Discussion Group
Quality Improvement in Maternity Services
15 babies a day: raising awareness about stillbirth and neonatal death

By Clea Harmer, Chief Executive, Sands

Every day in the UK, 15 babies are stillborn or die in the neonatal period, or to put it another way, one in every 141 babies dies before, during or shortly after birth.¹ Each one of these deaths represents a devastating loss for the parents and families; as one mother writes ‘the pain of losing a child cannot be explained only experienced’.²

However, these stark statistics are not well known and stillbirth and neonatal death remain taboo subjects, with many regarding it as inappropriate to discuss these issues with pregnant women and their families for fear of causing distress or alarm.³ This approach leaves parents whose babies die reporting a sense of isolation, unpreparedness and guilt, which compounds their grief.⁴ ⁵
Stillbirth and neonatal death – the facts

Despite a growing body of information and evidence relating to stillbirth and neonatal death, there are still many unanswered questions, with 50% of stillbirths recorded as being from unknown causes. Understanding why these deaths occur and translating this knowledge into practice is key in reducing the number of babies dying, and involves building a complex and multi-factorial jigsaw to identify the missing pieces. Further research is clearly needed, but also a comprehensive review of every stillbirth and neonatal death. One in three stillbirths occur at term and 60% of these (approximately 500 deaths a year) might have been avoided with improvements in clinical care.

Yet Confidential Enquiries show that in 75% of stillbirths at term, there was no evidence of a local review of care. Where reviews had been carried out, few followed national guidance or involved parents. If care around a death is reviewed honestly and within a culture that seeks to improve, the lessons learned are as important as identifying risk factors and underlying causes.

MBRRACE’s perinatal audit identifies specific risk factors for stillbirth and neonatal death. Black and Asian babies are more at risk, as are mothers aged over 35, teenage mothers and those expecting a multiple birth. Inequality plays an important but poorly understood role, with mortality rates 50% higher in the most socially deprived areas. But the number one modifiable risk factor is smoking, with one in five stillbirths associated with smoking.

The UK has a significantly higher rate of stillbirth and neonatal death than other comparable European countries, and evidence suggests that we are far from reaching an irreducible minimum for perinatal deaths. The UK’s annual rate of stillbirth reduction is up to three times slower than our better performing European neighbours such as The Netherlands, indicating that more could be done. Furthermore, mortality rates vary across the UK, from 4.9 per 1,000 births in some areas to 7.1 per 1,000 births in other areas, even after adjustment to allow for different population mixes, which suggests that quality of care plays some part. It is clearly important to understand why this variation exists and address these inequalities.

A priority for all

Despite the scale of the problem, it took the Kirkup Report and The Lancet’s Ending preventable stillbirths Series along with reports and lobbying from Sands, to raise wider awareness of the issues relating to stillbirth and neonatal death. These reports provided the incentive needed for politicians, clinicians, researchers and charities to focus on the imperative to reduce the number of babies dying.

In England, in November 2015, Jeremy Hunt, Secretary of State for Health, announced a national ambition to reduce the number of stillbirths and neonatal deaths by 20% by 2020, and by 50% by 2030. This, in addition to existing initiatives such as the National Maternity Review and Each Baby Counts, signalled a commitment to address the number of deaths. Similar initiatives have taken place across the devolved nations, with Stillbirth Working Groups being established in Scotland and Wales, and the Maternal and Infant Death Steering Group in Northern Ireland.
Current initiatives to reduce the number of stillbirths and neonatal deaths include:

1. **Each Baby Counts (RCOG)**
   The RCOG is bringing together lessons learned from local investigations undertaken after the death of a baby, in order to improve the quality of care in labour at a national level. The first report in June 2016 highlights the importance of including parents in reviews, and of introducing a perinatal mortality review tool to standardise reporting and the ability to learn and improve practice.

2. **Maternity Transformation Programme**
   Better Births, the report of the National Maternity Review, sets out a vision for maternity care to 'become safer, more personalised, kinder, professional and more family friendly'. Implementation of this programme supports Jeremy Hunt’s national ambition, and one of the nine workstreams focuses on promoting good practice for safer care. However, almost every single workstream will help the target, with continuity of carer, increasing choice and sharing data amongst these. In addition, the CCG Improvement and Assessment Framework 2016-17, which will provide information on the effectiveness of commissioning maternity services, has been designed to align with key themes from Better Births, and 'stillbirth and neonatal mortality' are one of four indicators that have been selected for use.

   Maternity care that involves parents being cared for by the same healthcare professionals that they know and trust, and which involves parents being given information that enables them to make the right decisions for themselves and their babies, will help to make a difference. As Dimitrios Siassakos outlines in this issue of *Perspective*, it is vital to listen to parents and take their concerns and views seriously. In addition, a maternity system that supports real learning and reflection and a drive to continually improve using individual and shared learning, can only benefit parents and their babies.

3. **Saving babies’ lives care bundle (NHS England)**
   The care bundle consists of four elements which have been shown to help reduce stillbirth and neonatal death; the strength of evidence for each of the elements varies, and there are some notable omissions such as detection of diabetes, but all maternity units, trusts and health boards are encouraged to adopt these measures:
   - Reducing smoking in pregnancy
   - Enhancing the detection of fetal growth restriction
   - Improving awareness of the importance of fetal movements
   - Improving effective fetal monitoring during labour

   Alongside these initiatives, parents need access to clear information to enable them to make informed decisions; campaigns such as Our Chance® and resources such as Sands’ new Safer Pregnancy website and ‘15 babies a day’ initiative aim to provide this.
What do parents need?

It is very important not to lose sight of the parents and their needs in the drive to improve care and outcomes. The national commitment to reduce the number of babies dying is reflected in the enormous generosity of bereaved parents who often focus on this aim themselves, stating their belief that no parent should have to go through what they went through. But bereaved parents also have their own needs at a time of devastation and profound grief, and we must do all we can to meet these.

Bereavement care

The impact of the quality of bereavement care that parents receive from health and social care professionals cannot be underestimated; nothing can remove the grief that many parents will feel, but good care can make a devastating experience feel more manageable. However, health care professionals need both the facilities and the training to be able to offer this support. Sands’ recent audit of bereavement care\(^{19}\) showed that one in three trusts and health boards do not have a dedicated bereavement room in each maternity unit they cover, and 33% do not have a bereavement midwife. Clearly, more needs to be done to improve the bereavement care that all parents receive.

Support

The support that parents want and need obviously varies between individuals, but the overriding aim should be to enable them to access the right care at the right time. Parents often find making memories and creating a memory box helpful, or accessing information from leaflets or websites. For some, groups that provide face-to-face peer support are invaluable, whilst others find peer support through online forums.\(^{20}\) Some parents may also need counselling. The most important thing is to understand what parents’ needs may be and then to be able to help them access what is available at an extraordinarily difficult, painful and bewildering moment in their lives.

Acknowledgement

Parents need their babies to be acknowledged – using the baby’s name, talking about the baby, remembering key dates, creating memories, are all ways of doing this. The enormity of losing a baby needs to be acknowledged by family and friends, and also by the workplace.

To break the taboo of stillbirth and neonatal death

Parents talk about the isolation and loneliness they experience after their baby dies: friends cross the road to avoid having to talk to them, people expect them to ‘get over it’ and ‘move on’.\(^{21}\) In many ways stillbirth today is where cancer was 40 years ago, a taboo subject avoided by many. Whilst stillbirth remains hidden, not only is desperately needed comfort and support denied to bereaved parents, but the messages around safer pregnancy are not widely shared, preventing parents from making fully informed decisions.
As a practitioner

Practitioners working with parents in the antenatal and postnatal periods are in a privileged position — able to provide evidence-based information about stillbirth and neonatal death to all parents antenatally, but also parent-centred support to bereaved parents. The challenge for practitioners is to share information on stillbirth and neonatal death whilst still empowering women and conveying the normality of birth. But as with all challenging issues, promoting informed decision-making provides the key to allowing even the most difficult topics to be explored, and this is something that practitioners are very well-equipped to do.

Conclusion

We can increase our understanding of why 15 babies die every day; we can put this research into clinical practice; but until we involve and engage parents in understanding more about stillbirth and neonatal death we will not bring this figure down.

References

1. ONS data compiled from three sources:


5. Beck E. Why don’t people talk more about stillbirths? BBC News 22nd July 2016 Available from: http://bbc.in/2pcESfp


Definitions

**Stillbirth:**
A baby born at or after 24 weeks of gestation showing no signs of life

**Neonatal death:**
A liveborn baby who dies before 28 days after birth

Five ways you can help someone whose baby has died

1. **Talk about their baby** – ask them if they would like to spend some time talking about their baby. Sometimes people avoid the subject for fear of causing distress but many bereaved parents want their baby acknowledged and to hear their baby’s name.

2. **Let them know you are thinking about them** – a simple text, card or email will let them know you are thinking about them and their baby. If you know them well, you might want to call them and ask how they are. It’s okay to ask ‘How are you?’

3. **Offer practical help** – when a baby dies it can be very hard for parents and families to do everyday tasks such as walking the dog, going shopping or cleaning the house. If you are in a position to do so, offer to help in a specific, practical way.

4. **Remember their baby** – light a candle for their baby during Baby Loss Awareness Week and send a photo of it to let them know you’re thinking of them. Remember their baby’s birthday and send them a ‘thinking of you’ message.

5. **Give them the Sands Freephone helpline number**
(tel 0808 164 3332, email helpline@uk-sands.org.uk) – the experienced helpline team offer a safe, confidential space for anyone affected by the death of a baby. We offer non-judgemental, compassionate support by telephone or email and may be able to refer them on to a local Sands group in their areas.
To improve bereavement care we must first listen to parents

Dimitrios Siassakos, Consultant Senior Lecturer in Obstetrics, Southmead Hospital, Bristol

The impact of stillbirth on parents

Stillbirth was neglected until recently.¹ No health system can be proud of the care it provides when the death of babies before or after birth continues to go unnoticed, and their parents’ needs are not acknowledged. Something must be done. Stillbirth can cause significant emotional and psychological harm, much of which is avoidable.

The first step is to recognise the impact of stillbirth on families and society. Systematic reviews of literature for The Lancet’s Stillbirth Series 2016 showed the wide-ranging impact of stillbirth.²³ Women with stillborn babies suffer from severe psychological symptoms and depression; descriptions that their body felt like a grave are not uncommon. Relationships with partners become strained, and pressures to achieve or postpone another pregnancy can emerge. Attachment with previous and future children, including the surviving twin (when one baby dies and the other survives), becomes difficult, with exaggerated worries and fears affecting bonding. Some women withdraw from social circles and activities while others over-engage in order to avoid...
grieving, and instead prolong the process. At the extreme, some families or cultures ignore stillborn babies, leaving women to grieve alone. Even worse, some women become stigmatised and cast aside by family and society.

Although many families do find some balance and start a new life after stillbirth,² healthcare professionals should strive to provide the best possible support to every parent and family.

**Every bereaved parent has the right to good care**

Sadly, the support for bereaved parents is not always as good as it could and should be. A systematic review of bereavement care worldwide revealed gaps, errors and inconsistent support for both parents and the maternity staff caring for them after stillbirth.⁴ Limited public awareness of stillbirth caused shock to parents who were totally unprepared. Providing care for bereaved parents was often not a priority following a stillbirth, and partners’ needs were seldom recognised. The behaviours and actions of staff had a memorable impact, yet often, staff had neither the knowledge nor the skills to meet parents’ needs. In the absence of training, staff chose to hide behind ‘ritualising’ guidelines, distancing themselves from parents and focussing on practical tasks instead of offering emotional support.

In the UK, the INSIGHT study⁵ explored these problems in depth to identify parent-driven and parent-centred solutions: listening to the voices of parents and staff who want, but cannot always provide, good care. The INSIGHT study produced a detailed investigation of current issues in bereavement care, and crucially, collected evidence to help design improvements, showing:

- Inconsistency in the management of parents with reduced or absent fetal movements, leading some to liken their haphazard journey to a ‘game of snakes and ladders’. Parents and staff recommended developing a clear referral and management pathway to address this lack of co-ordination and structure.

- A very wide range in the time interval before confirmation of a stillbirth diagnosis, sometimes with a long delay, particularly out of hours. Recommendations included training in using ultrasound but also in empathic communication before, during and after the scan. For example, and similar to best practice in obtaining consent for any procedure, staff should warn parents in advance about what may occur during the scan, including long silences. These moments can feel awkward for parents and might cause less trauma if they do not come as a surprise.

- Wide variation in decision-making, with a common characteristic being decisions made for parents instead of with parents, for example, if they asked for a caesarean birth. In such instances the first step in joint decision-making is to recognise the reasons why parents might ask for a caesarean, without forgetting that mothers (if they have not given birth yet) will still have a baby inside them. Rather than focussing discussion on maternal wellbeing or future pregnancies, the correct approach is to explore the parents’ reasons and establish rapport before discussing all options. For example, for many parents the fear of having a vaginal birth for a stillborn baby might be the result of inadequate preparation, a scenario so different to the exciting labour and live birth they had planned and anticipated. Developing a new birth plan for the stillbirth might be considerably more
helpful in alleviating their fears than raising as a reason to decline their request, the increased, yet still low, risk of stillbirth in future pregnancies after a caesarean.

- Inconsistent discussion about post-mortem examination, due to lack of training for staff on how to approach the topic with parents.
- Despite the many inconsistencies and large variation in management, solutions were not necessarily complex.

In summary, the INSIGHT study showed that we must listen to every voice and strive to respond with consistency. There is urgent need for an evidence-based integrated care pathway that starts with detection of reduced fetal movements and continues beyond discharge from the hospital and into community care.

**Involving bereaved parents in improving care**

While it is extremely useful to capture the voices of many parents, in-depth studies such as INSIGHT do take time. However, it is important to learn from every single death contemporaneously, and use the lessons to improve care today and tomorrow. Improvement in stillbirth prevention and care has become a national priority in the UK. But the failure to involve parents, and even to notify parents about hospital reviews of their baby’s death\(^6\) brings into question the usefulness of any proposed improvements.

To bring about proper change we must listen to all voices first. While many bereaved parents may want to be involved in service improvements,\(^2\) research,\(^2,7\) and hospital reviews, others might wish to defer or avoid such involvement, as shown in the recent PARENTS I Study.\(^8\) In order to involve parents in a meaningful way requires staff training, standardisation of processes, and evidence-based tools.

The UK is pioneering such parental involvement in hospital perinatal mortality reviews. The new PARENTS II Study is gathering evidence to support development of a standardised national process of bereavement care, led by North Bristol NHS Trust in collaboration with MBRRACE-UK and partners: the University of Bristol, the International Stillbirth Alliance and the University of Manchester. PARENTS II will implement the incorporation of input from parents into the hospital review process following the death of a baby, initially in two UK hospitals. The findings will subsequently inform the development of a standardised process for all UK hospitals which is structured yet flexible, and transparent yet considerate. The aim is to improve the review process, help parents deal with grief more effectively, and drive improvements in patient safety by highlighting errors in care as well as good practice.

In the meantime, one step would be for healthcare professionals to inform all parents that hospital reviews do exist and offer a summary of the discussions; at least until the evidence from PARENTS II is available to help design a process that is acceptable and useful.

Let’s listen to every voice, learn from every baby’s death, and design better care together.
Conclusion
Every bereaved parent is entitled to good care. Every bereaved parent is entitled to have the option to help generate lessons for improvements in care. At the same time, every member of staff is entitled to training and support, so that they can in turn support parents effectively. To improve bereavement care, we must understand the needs of parents, the needs of staff, and the needs of the health system. Let’s listen to every voice, learn from every baby’s death, and design better care together.

Summary of key points
• The impact of stillbirth is wide and far-ranging. The needs of bereaved parents are significant, but were often neglected, until recently.
• There is variation in the care for bereaved parents in the UK and worldwide. Good examples exist of excellent communication and parent-centred care, but there are also instances of parents’ needs being ignored, delayed management, clumsy and inappropriate interactions with caregivers, and one-sided decision-making.
• To improve bereavement care and provide consistency and flexibility in approach, we need to understand parents’ needs; develop tools to guide them through their difficult journey; and train staff to support parents and become their advocate.
• To achieve better care we need to involve parents in initiatives to understand and address the problems, and in recognising, rewarding and disseminating excellent care.

Quotes from bereaved parents
• ‘Something wasn’t quite right.’
• ‘We weren’t really in a situation where there seemed to be any decisions to be made.’
• ‘In all honesty, I could see they [staff] were struggling.’
• ‘I could not stand my body - it had killed my child.’
• ‘I have moments when I apologise for killing our daughter.’
• ‘I was devalued as a bad daughter-in-law because I could not give birth to a heir.’
• ‘Many treated me like a leper and still do.’
• ‘Her death has made me realise not to take things for granted such as my living children.’
• ‘It’s important that they explain everything and not just leave me to sit there thinking what’s going on.’
References

When is the baby moving enough in pregnancy?

By Denise Stanford-Bell, NCT antenatal teacher and tutor

How do mothers experience fetal movements?

The baby’s pattern of movements in the uterus is determined by its neurological development and metabolic state. The mother will usually feel movements from about 18-20 weeks of pregnancy for a first baby and often earlier with a subsequent pregnancy. Movements are often first felt as a ‘popping’ or ‘bubbles’ sensation that changes into more defined baby movements as their baby grows. Many women will find their baby develops a pattern of activity and rest, though this is not the case for everyone which can make monitoring difficult. For most women, their baby’s movements will continue to increase up to 32 weeks of pregnancy and the amount will then stay the same but they may change in nature as the baby’s size increases e.g. more squirms as the baby has less and less room to manoeuvre. The baby’s position in the uterus and the position of the placenta will affect the movements felt by the mother and no particular number is deemed to be ‘correct’. Women should be informed early on in pregnancy about the importance of monitoring movements as an indication of fetal wellbeing so that the message is reinforced. An anterior placenta will affect women’s
ability to monitor movements and they should ask for midwifery advice on how to feel for movements.

**Why is it important to think about fetal movements**

Regular movements of the baby after 20 weeks are a sign of the baby’s well-being and reduced movements have been linked to fetal compromise, intrauterine growth retardation (IUGR – see note below) and stillbirth. IUGR is defined as a condition where the fetus is unable to achieve its genetically determined potential size and differs from other small for gestation age fetuses. There is no agreement on what number of movements ‘should’ be felt. An Israeli retrospective study found that reduced fetal movements were linked with amniotic fluid disorders and were reported less by multiparous women (second and subsequent baby) which they conjectured could be due to less focus on fetal movements. Interestingly, the NICE antenatal guidelines state that fetal heart auscultation (listening to the baby’s heart rate) in pregnancy should not be routinely carried out as it can give false reassurance, especially where reduced fetal movements (RFM) have been reported. This is because it gives a recording in the moment and cannot evaluate the baby’s overall wellbeing. Women can request monitoring with a Sonicaid fetal doppler or a Pinard stethoscope, but it should not be replaced by a mother’s awareness of her baby’s movements.

**What’s normal and what do we mean by reduced fetal movements?**

There is a lack of agreement in research over what constitutes reduced fetal movements, which makes a consensus over advice difficult and may have resulted in the wide variation in best practice throughout the country. There is also a wide variation in local maternity guidelines and how much these adhere to national recommendations. The RCOG Green-Top Guideline states that maternal perception is very important and should be taken seriously, as 55% of women who experience stillbirth perceived RFM. The organisation ‘Kicks Count’ has a webpage in line with RCOG guidelines. The RCOG states that if a change of movements is noticed, then the mother should lie on her left side and movements up to 10 counted in a two-hour period. If this does not occur, then the mother should seek immediate medical advice about RFM from a midwife (and not leave a message on an answer machine intended for non-urgent messages). The RCOG’s patient information goes on to give more useful information about the stage of pregnancy and repeat experiences.

**What are the statistics linking reduced fetal movements to stillbirth?**

The reduction, or absence, of fetal movements is a recurring factor in stillbirths. and found a 2-3 fold increase in perception of RFM and risk of stillbirth when mothers presented with RFM. Yet 70% of pregnancies with a single episode of RFM go on to be healthy pregnancies and birth. Women who have normal results after investigations
and resumed movements following a presentation and history of RFM, should always be reassessed if they experience repeat episodes.2

**Risk factors for stillbirth**
- Known IUGR or SGA (small for gestational age)
- Obstetric cholestasis
- Diabetes
- Fetal abnormalities
- Hypertension
- Smoking
- Illicit drug use
- Low socioeconomic group
- Post-term pregnancy (>42 weeks)
- Previous stillbirth
- Body mass index > 35 kg/m²
- IVF
- Maternal age > 40 years3

**How can fetal movements be monitored?**
The evidence suggests that midwives should ask pregnant women regularly about fetal movements5 but counting movements should not be recommended. However, there is a wide variation in practice. The Cochrane review, supported by another systematic review12 does not recommend using kick charts, counting strategies or hormonal tests.13 Winje et al12 noted an increase in hospital admission and increased maternal anxiety where interventions were used, although perinatal death as not measured and more research was recommended. A study in Norway involving the use of kick charts found a reduction in the stillbirth rate of 50% compared to other surveillance activities.14 However, it also increased the hospital admission and caesarean birth rates, which may impact on the best policy choice going forwards. Using customised growth charts is another way of monitoring fetal wellbeing.6 **Saving babies lives: a care bundle for reducing stillbirth**15 recommends a number of strategies to reduce stillbirth including increased awareness of fetal movements and personalised growth charts. The latter is being rolled out in many NHS Trusts via the Gestation Network and the Perinatal Institute. This will warrant monitoring due to concerns over increasing induction rates. However, in one study 8.1% of mothers who reported RFM, when asked to count movements in the last three months of pregnancy, went on to have healthy babies16 and RFM were found to be associated with employment, lack of exercise and lying back (supine position) when counting movements. These issues should therefore be taken into consideration when educating women. After a repeat episode of RFM an ultrasound scan to detect if IUGR is present and the underlying cause is recommended.2 Sands are part-funding the AFFIRM study to discover whether promoting increased awareness of RFM reduces stillbirth.
What should mothers do if they are worried?

Mothers should rely on their senses and instincts and always seek advice and an antenatal check if they have concerns. The RCOG guidelines\(^2\) advise that women who have reported with a history of RFM are assessed firstly with a cardiotocograph (CTG) if over 28 weeks pregnant. In conjunction with a CTG a biophysical profile may done with repeat experiences, using ultrasound to measure muscle tone, movement, breathing, and the amount of amniotic fluid around the baby. If under 28 weeks, then a full antenatal examination and listening to the baby’s heart rate via auscultation (listening with a Doppler monitor) is recommended. Anecdotally, midwives will often check that women are eating and drinking well and this can affect their baby’s movements. If over 28 weeks of pregnancy the CTG is normal and the mother’s perception of RFM has resolved, mothers should then be advised that with a subsequent episode of reduced fetal movements of less than 10 movements within two hours, to contact their maternity unit.\(^2\) However, as there is no agreed definition of RFM and for those extremely active babies, an arbitrary perception of 10 movements per two hours may not indicate fetal wellbeing and in fact may lead to women failing to seek prompt medical assessment. So, a pattern of movements which is unusual for mothers would seem to be the key message.

Implications and practical tips for practitioners working with parents

- NCT practitioners are not midwives in their role and should always refer to a midwife/maternity unit if a mother has concerns about RFM.
- Women should always rely on their instincts and seek medical help and an antenatal check if they are worried about their baby, however many times this may happen.
- Find out what the policy is in your local area and see if you can contribute to local practice through an MSLC or User Group: [https://www.npeu.ox.ac.uk/mbrace-uk/sharing-practice](https://www.npeu.ox.ac.uk/mbrace-uk/sharing-practice)
- This topic could be covered in an antenatal course if it arises in discussion, and through sharing evidence and RCOG guidance during sessions on wellbeing in pregnancy and when to contact a health professional. Some women feel that this topic is not covered adequately during their antenatal care, so sharing information on Our Chance for a Safer Pregnancy campaign and Best Beginnings Baby Buddy App will give parents information they can act on if they choose to.
- Perhaps it is all in the education of women and rather than focussing solely on the risk of adverse outcomes, women could be encouraged to increase awareness in what one Swedish study called ‘mindfetalness’\(^17\) where there was a higher mean score of pre-natal attachment alongside maternal calmness. Perhaps if attachment and relationship with their baby were focussed on it would be a more positive experience.
Useful resources and further info


Kicks Count
http://www.kickscount.org.uk/mums/your-babys-movements/

Our Chance http://ourchance.org.uk/

Tommy’s. Reduced fetal movements: My baby’s movements have slowed down. Available from: http://bit.ly/2qJKZaQ

MBRRACE-UK: Sharing practice
https://www.npeu.ox.ac.uk/mbrrace-uk/sharing-practice

This article focuses on singleton pregnancies and acknowledges that issues for twins and multiples may be different.

Note: Although the terms IUGR and SGA are often used interchangeably, they are not synonymous. A newborn may be labelled SGA according to reference population standards if the newborn is constitutionally small but otherwise normal (e.g. born to parents who are small and/or into an ethnic population that is smaller than the reference population). Alternatively, a fetus with delayed growth late in gestation (asymmetric IUGR) may not have a reduction in birth weight significant enough to be classified as SGA.18
Spotlight

Spotlight on Research

NCT antenatal teacher Amanda Waterman outlines the findings of the Better Beginnings review of evidence around improving health before, during and after pregnancy.

Better Beginnings is a review of evidence from research funded by the National Institute for Health Research-funded on improving health before, during and after pregnancy and ultimately to provide lifelong health benefits for women and their children. The focus is on smoking cessation, healthy diet and weight, and addressing complex social needs. As a review it is easily accessible and has well summarised points to provide guidance on practice for commissioners, primary care, maternity services, public health and local authorities. It has an easy-to-read layout and a particularly useful online edition containing 'Read more' links to additional information, as well as comprehensive Appendices with a summary of the research projects.1

Opportunities to improve health before, during and after pregnancy

Modifiable risk factors for pregnancy and future child health are:

• Improving health before pregnancy
• Stopping smoking
• Eating a healthy diet including folic acid supplements
• Being a healthy weight and physically active
• Breastfeeding
• Avoiding alcohol and illicit drug use
• Addressing mental health problems and psychosocial stress
• Supporting families with multifaceted approaches

Source: reference 1

The review launch on 28 February 2017 was well attended by midwives, researchers, commissioners and user representatives. As a user representative and NCT antenatal teacher, I was interested to hear speakers’ views about both the findings and limitations of the research. Round-table discussions with peers aimed at producing questions for future research was very enlightening: a key areas not evident in the current research was the impact of partners’ support on women’s behavioural attitudes towards health and wellbeing. The following sections are summaries of the review’s overall findings and conclusions.
Improving Health Before Pregnancy

Women who are in good health before pregnancy have the best start to their pregnancy and the best outcomes. Women who access services and adopt healthy behaviours early on can reduce the risk of complications, for example, by continuing with existing health behaviours or (for women with long-term health conditions) looking for advice on how to optimise health in pregnancy. Participants at the launch event noted that this preconceptual period could be as early as secondary school age for some girls, and that there needs to be wider general public health awareness about the importance of healthy diet and weight.

Stopping smoking

Given that the effects of smoking can result in poorer pregnancy outcomes, the review looked at studies on secondhand smoke effects and ongoing studies on smoking cessation for women. The use of nicotine replacement therapy as an aid to smoking cessation showed mixed results in terms of efficacy. But with regard to effects on children, one study showed no development impairment in two year olds exposed to nicotine replacement therapy in the womb. The NHS smoking cessation service exists to support women who wish to stop smoking and will be offered by the midwife at the booking appointment. Practitioners working with parents during pregnancy may find it useful to check out how this service operates in their local area. Is there a coordinated team who support women? What support is there for partners who wish to give up smoking?

Healthy diet and weight

Vitamin D and folic acid are recommended. There is ongoing research into whether changing diets for women with obesity during pregnancy can reduce some the risks of some complications, however reducing weight after pregnancy can reduce risks for the woman and future pregnancies. It can be a sensitive point to discuss in classes, so consider open group discussions and sharing ideas about how everyone stays healthy and active during pregnancy.

Breastfeeding

Health care providers and communities adopting an integrated support network for breastfeeding mothers are more effective in improving duration of breastfeeding, according to the Better Beginnings review. Beyond previous tried and initiatives, such as financial incentives, newer ideas include use of hospital beside or ‘side-car’ cots to help improve breastfeeding initiation. Ongoing research addresses areas with low breastfeeding rates to see if mobile phone text messages and direct contact from infant feeding supporters from 28 weeks gestation will increase initiation. NCT can, and is, play a large part in supporting breastfeeding initiatives. Some NHS Trusts have volunteer breast-feeding peer supporters, and there are local breastfeeding groups run jointly by health professionals and NCT breastfeeding counsellors.
Complex social needs

Complex social needs, including alcohol and drug use, mental health problems and violence against women, is a specialist area requiring bespoke care, but more importantly, clear care pathways in which women can access. Much of the success in caring for affected women is the early identification and support. New research is evaluating the different approaches to providing this support. NCT actively encourages practitioners to have open discussions with parents about postnatal depression and to signpost to services. The charity is also campaigning for policy changes through our Maternity Services Liaison Committee (MSLC) roles. Some Trusts will have specialist consultants and midwives dedicated to supporting women with complex social needs.

Supporting families using multifaceted approaches

Research on one-to-one support by birth doulas for disadvantaged women has shown beneficial effects; ongoing studies are testing the use of incentives in order to reduce inequalities and improve engagement. This is a challenging area for NHS Trusts, but previous examples of excellent practice are highlighted through the All-Party Parliamentary Group on Maternity Awards (http://bit.ly/2qQXy1r)

In a time when many women feel overwhelmed, the Better Births review highlights the issues women face. More importantly, it represents a new initiative to start pushing for, and providing, better care, support and services for women. As practitioners and user Representatives involved in MSLCs, we can use the evidence and ideas to initiate changes in policies to ensure clear pathways of care for women.

Reference


Amanda Waterman joined NCT as a local volunteer in 2006, when her son was 2 years old, to promote support for stay-at-home fathers. She worked at the London office of NCT from 2007-2012 as a volunteer co-ordinator, and qualified as an antenatal teacher in 2011. Amanda is now pursuing her career as a midwife after qualifying in 2015, and is passionate about integrating research into practice.
Prevention of stillbirth and management of stillbirth risk

By Alexander Heazell, Senior Clinical Lecturer in Obstetrics and Clinical Director, Tommy’s Stillbirth Research Centre, University of Manchester, UK

Stillbirth describes the death of a baby before birth, and is a tragic event with long-lasting impact for mothers and their families. It has been described as a ‘silent problem’, frequently not discussed by healthcare professionals or in online or printed information for pregnant women and their families. This lack of information compounds parents feelings of isolation if they experience a stillbirth, with many saying, “The first time I knew this could happen was when it happened to me.” This means that women may not appreciate the underlying reasons for health promotion (e.g. smoking cessation) or intervention. Clearly, the topic of stillbirth is a sensitive one that needs to be informed by relevant, contemporary evidence about the causes and risk factors for stillbirth.

There are 2.6 million stillbirths each year throughout the world. Although the majority of cases occur in resource-poor countries, stillbirth is perhaps surprisingly more common in the UK and other high-income countries. There are about 3,250 stillbirths in the UK each year, with one in 220 occurring after 24 weeks of pregnancy. In high-income countries stillbirth...
rates range widely from 1.3 to 8.8 per 1,000 births after 28 weeks of pregnancy, in Iceland and Ukraine, respectively; the UK ranks 24th out of 49 high-income countries. Even within the UK there is huge variation in stillbirth rates from 4.9 to 7.1 per 1,000 births after 24 weeks of pregnancy. This reflects variations in the frequency of risk factors for stillbirth in different regions of the UK.

Stillbirth causes and risk factors

The causes of stillbirth are classified and recorded using information from mothers, their medical records and investigations after stillbirth including: post-mortem, placental examination and blood tests on the mother. In the UK, more than 90% of stillbirths occur before labour starts. The most frequent causes of stillbirth are foetal growth restriction (when the baby does not grow as expected), placental abruption (when the placenta separates from the inner lining of the womb), placental insufficiency (when the placenta does not meet the needs of the growing baby), infection and congenital abnormalities. Despite investigation, a cause is not found in between 15.2% and 46% of stillbirths. The importance of foetal growth restriction and placental insufficiency underpin many of the current initiatives to reduce stillbirth in the UK.

A risk factor describes any attribute, behaviour or characteristic of an individual that increases the likelihood of developing a condition. Risks are usually expressed as an odds ratio or relative risk, which compares the risk in one group of women with another. When considering stillbirth, risk factors can be divided into those that can be modified in pregnancy and those that cannot. Important non-modifiable risk factors include maternal age (<16 or >35 years), black or minority ethnicity, social deprivation, low educational attainment, a stillbirth in a previous pregnancy and medical problems in the mother such as diabetes or high blood pressure. For mothers whose risk factors cannot be modified, their situation may be improved by specialist maternity services which facilitate access to care or additional surveillance (usually measurement of baby’s growth by ultrasound scans). Modifiable risk factors include cigarette smoking, drug use, mother’s perception of reduced fetal movements and, potentially, mother’s sleep position.

Improving the odds for mother and baby

These aspects of mother’s behaviour or symptoms can have a significant impact. Cigarette smoking has a ‘population attributable risk’ of 7%, which means if no one smoked during pregnancy there would be 7% fewer stillbirths. Importantly, if mothers stop smoking before 16 weeks of pregnancy the risk of stillbirth is the same as for non-smokers. If the mother stops smoking she reduces the risk of not only foetal growth restriction and cot death but also her own longer-term health risks. Therefore, interventions to reduce cigarette smoking have a significant benefit for both mother and baby. Smoking cessation is the first element of NHS England’s Saving babies’ lives care bundle. Support for smoking cessation includes carbon monoxide testing of all pregnant women at their antenatal booking appointment, and where appropriate, referral to a stop smoking service or specialist based on an opt out system. Recently, a scheme in the North East of England
(BabyClear) has shown that applying the NICE guidelines and training staff can significantly reduce smoking rates during pregnancy.\textsuperscript{13}

The largest risk factor for stillbirth is a baby that is smaller than expected (termed small-for-gestational age, or SGA), and includes babies who have foetal growth restriction. The risk of stillbirth for an SGA baby is almost eight times greater than for a normally grown baby, but if SGA is identified the risk reduces five-fold.\textsuperscript{14} Consequently, the second focus of the saving babies lives care bundle is identification of SGA babies.\textsuperscript{12} For most women at low risk of foetal growth restriction, growth will be measured by symphysis-fundal height by their midwife. If this indicates little or no growth then the mother would have an ultrasound scan to measure baby's size. If the baby is small then additional tests would be performed including measurement of the liquor around the baby or umbilical artery Doppler, which measures blood flow from baby through the placenta.\textsuperscript{15} Mothers who have significant risk factors for foetal growth restriction would be offered ultrasound scans to measure foetal growth regularly throughout pregnancy. This approach appears to reduce stillbirth incidence and attempts to separate babies that are small but growing normally, from those whose growth is reduced.

One important symptom of placental insufficiency is a reduced fetal movement. Women who attend hospital with reduced foetal movement have a two-to-three-fold increased risk of stillbirth.\textsuperscript{16} A reduction in babies' movements has been linked with stillbirth for many years; laboratory studies suggest that this relates to reduced placental function,\textsuperscript{17,18} which would explain the link between reduced movements, foetal growth restriction and stillbirth. There is some evidence that the risk of stillbirth increases with the number of episodes of reduced movements.\textsuperscript{19} Unfortunately, however, two Confidential Enquiries into stillbirths before labour described a significant number of cases when a lack of information or incorrect management of reduced movements contributed to stillbirth.\textsuperscript{20} As babies develop their own movement patterns there is no definition of 'normal movements'. Mothers should instead be encouraged to attend their maternity unit/care provider if concerned that the movements are reduced or absent. They should also receive information that babies should move as usual right up until the start of labour and that it is not 'normal' if babies move less in late pregnancy. For mothers with reduced foetal movements current guidance recommends that a heart rate trace be performed to exclude immediate complications (present in 2-4% of women with reduced foetal movements) and an ultrasound examination if there are risk factors for foetal growth restriction.\textsuperscript{21} Mothers should be informed of the results and an individualised plan made with her if a problem is found. If all appears normal, then mothers should be encouraged to present with further concerns about foetal movements.

Another risk factor for stillbirth after 28 weeks of pregnancy is a mother’s sleeping position: if she lies flat on her back she has a 2-6-fold increased risk, according to studies in New Zealand, Australia and Ghana.\textsuperscript{22,23} This may be because lying flat compresses the mother’s inferior vena cava, the large blood vessel returning blood to the heart. This in turn reduces how much blood can be pumped to the uterus. A change in the mother’s sleep position can be brought about with education. If further studies, currently underway in the UK and elsewhere, confirm the association between sleeping flat on the...
Mothers who are at increased risk of stillbirth may be offered the choice of induction of labour or elective Caesarean birth before their expected due date. The stage of pregnancy at mothers may be offered intervention will depend on their individual circumstances. In part, these decisions reflect that after 37 weeks of pregnancy, induction of labour is associated with a reduction in stillbirths and neonatal deaths, and tests become less helpful in determining individual stillbirth risk. Although parents may be concerned about increasing intervention, induction of labour after 39 weeks of pregnancy is not associated with a decrease in straightforward births, and may reduce the number of Caesarean and assisted vaginal births.25

In conclusion, to reduce the incidence of stillbirth, we need better information regarding the causes and risk factors. We must also increase awareness of stillbirth in order to reduce the isolation that many bereaved parents and families feel, as well as to help mothers understand the reasons behind health messages to stop smoking, be aware of their baby’s movements and report abnormalities. As maternity care develops, one hope is that better tests will be devised which maximise the detection of babies at risk of stillbirth, and minimise the impact on otherwise healthy pregnancies.

References


Endocrine disrupting chemicals and breast cancer: reducing risk for babies and infants

By Jack Brown, Senior Policy and Campaigns Officer, Breast Cancer UK

Parents may come across media stories about endocrine disrupting chemicals (EDCs) – chemicals that can interfere with the human hormone system and may cause disease in humans. This article describes how we might be exposed to them, including during pregnancy and childhood, and their possible effects on human health. It reviews the evidence linking EDCs to human health problems with a focus on their potential link to breast cancer. Finally, it outlines practical steps that parents can take to reduce the exposure of their children to EDCs in utero (in the womb) and during infancy.

How do EDCs affect human health?

Endocrine disrupting chemicals can interfere with the normal functioning of the endocrine (or hormone) system by mimicking or blocking the action of hormones naturally produced by the body. This ability to disrupt the normal functioning of the body’s processes can potentially cause adverse health effects, including some cancers.¹
EDCs can:
• Act as 'hormone mimics', and induce chemical responses associated with natural hormones
• Act as 'hormone antagonists', which prevent natural hormones from exerting their normal effect
• Alter the concentration of the body's naturally circulating hormones or its hormone receptors
• Cause ‘epigenetic’ changes that alter the expression of genes (how much product a gene produces), but not its DNA sequence. Such changes may be inherited and can adversely affect normal development.

How does the media describe EDCs?
Endocrine disrupting chemicals make newspaper headlines, but the articles can use alarming language and do not always explain properly what EDCs are, or explore fully the evidence linking them to human health risks. This kind of coverage can lead people to either dismiss the problem of EDCs out of hand, or to panic about the health risks.

How are we exposed to EDCs?
Some EDCs, for example phytoestrogens found in plants, are naturally occurring compounds. However, most are synthetic (man-made).
• EDCs are present in a wide variety of everyday products, such as:
  – Cosmetics and personal hygiene products
  – household cleaners
  – plastic containers and packaging
  – garden pesticide sprays
• They are present in polluted air, soil and water, because of traffic fumes, pesticide runoff, chemical leaching from landfill, and sewage discharge.
• EDCs can enter the human body when we consume food and water, through our skin from use of personal care products, or through breathing in dust particles.
• EDCs are commonly detected in body tissues and fluids. For example, bisphenol A (BPA) is used to make polycarbonate plastics and has been routinely found in human urine, blood, amniotic fluid and breast milk.

What are the potential health risks linked to EDCs?
Many scientific bodies and organisations, including the Royal College of Obstetricians and Gynaecologists, the British Endocrine Society, the World Health Organization, and the European Environment Agency, hold the view that EDCs are linked to a range of health problems – although the evidence is mostly circumstantial and based on animal studies, and the link has not been proven. The potential damage includes harmful developmental, reproductive and neurological effects as well as several cancers that are affected by our hormone system, such as thyroid, prostate, ovarian and breast cancer.
**In-utero exposure and breast cancer**

Hormones influence the growth of a baby inside the womb and after birth, and need to be at specific concentrations in different tissues for normal development to occur. There is some evidence that *in-utero* exposure to certain EDCs can affect breast development and may increase the risk of developing breast cancer later in life.

Some EDCs can increase the risk of breast cancer by:

- Inhibiting post-natal breast development causing a lack of response to hormones\(^2\)
- Increasing breast tissue density\(^2\)
- Increasing the sensitivity of the breast to carcinogens\(^3\)
- Binding to oestrogen receptors and mimicking the action of natural oestrogens.\(^4\)

The use of diethylstilbestrol (DES) is an example of how *in-utero* exposure to EDCs can affect health. DES was once used by pregnant women to help prevent miscarriage, but many years later it was found that exposure to DES increases breast and genital cancers in exposed women and their daughters.\(^5\)

**Other health concerns**

EDCs may also be linked to other health problems such as infertility, miscarriage, obesity, autism and diabetes.

**What is the evidence that EDCs affect human health?**

Currently, much of the evidence on the health effects from EDCs comes from research using animal models or cell culture and studies of occupational exposures. What is clear, however, is that more research is needed to fill the gaps in our knowledge.

**Laboratory studies**

Animal studies have shown that certain EDCs can disrupt hormone interactions and cause cancer. For example, studies in rodents suggest *in-utero* exposure to BPA increases the risk of mammary gland tumours.\(^6\) However, these studies do not prove that the same chemicals cause breast cancer in humans.

**Workplace exposure studies**

Occupational studies of people who have been exposed regularly to EDCs in the workplace show that exposed workers are more likely to get endocrine-related diseases such as breast cancer.\(^7\) The weakness of these studies, however, is that they examine levels of exposure that are not typical for most people.
Effects on wildlife

The detrimental effects of EDCs amongst wildlife have been known for several decades and could indicate possible long-term effects in humans. They include ‘testicular feminisation’ in fish and thyroid problems and cancers in higher animals.8

Epidemiological studies

Studies of the human population that link environmental chemical exposure to disease risk are the most robust way to demonstrate if EDCs affect human health. Some studies have demonstrated a disease link,9 but they are difficult to undertake because EDCs are so common in our environment, and it is difficult to find a ‘control group’ that has not been exposed to EDCs, for comparison. Also, studies need to be performed over a long period and to consider numerous EDCs. Many factors could increase the risk of a disease, and so isolating the role of a specific chemical is challenging.

Uncertainty

There are unanswered questions surrounding EDCs and their effects, including precise details of how EDC exposure results in disease, which chemicals might pose a risk, and how much of a risk they pose at low doses or in combination with other compounds. To add to the uncertainty, around 1,000 chemicals are known or suspected of interfering with the endocrine system,10 but only a small fraction of these has been investigated in tests capable of identifying harmful effects in living animals.

Communicating the risk from EDCs to parents

The level of risk

It is important to note that we do not know if all EDCs pose a health risk; some may pose little or no risk at concentrations we are routinely exposed to. Other factors, such as age at exposure, how often and for how long a person is exposed, which EDCs they are exposed to, at what concentration and in what combination with other EDCs are likely to be important in determining risk.

What can parents do to reduce exposure to EDCs?

Whilst parents cannot avoid all EDCs, they can take some simple, practical steps to help reduce their exposure and that of their children.

• Avoid storing or cooking food in plastic and buying plastic children’s toys, particularly plastics labelled with the recycling codes 3 (polyvinyl chloride) and 7 (other plastics) as they may contain phthalates or BPA – both known EDCs which are released over time
• Wash fruit and vegetables well to help reduce any residues from pesticides and if possible buy organic
• Choose cleaning products that are ‘fragrance-free’ or contain natural fragrances. Synthetic fragrances (sometimes described as ‘musk’ or ‘parfum’ on labels) can contain EDCs such as synthetic musks and phthalates
• Avoid using all antibacterial soaps and toothpastes that contain triclosan, which will be identified on the ingredients list
Avoid using pesticides in the garden, especially those containing glyphosate.

Vacuum and damp dust regularly, as dust can absorb EDCs and is a common route of exposure, especially for young children.

Summary and conclusion

There is growing evidence linking EDCs to some health problems, including breast cancer. EDCs are common in our environment and are used in many everyday products. Whilst it is thought that current exposures to EDCs are relatively low, it is impossible to avoid them all. If parents are concerned they can take some of the practical measures outlined in this article to help reduce their exposure.

Key points

- EDCs are chemicals that can potentially disrupt hormones and cause adverse health effects, including some cancers.
- Media coverage of EDCs is often alarmist but not always informative.
- Many EDCs are man-made and are found in many consumer products as well as polluted air, water and soil. They are commonly detected in the human body.
- Many scientific organisations have linked EDCs to certain health problems. Exposure of babies in utero and of infants to EDCs may have health implications in later life, potentially including an increased risk of breast cancer.
- There is uncertainty about how EDCs affect our hormones and how much of a risk they pose. The evidence is mostly from animal and cell culture studies, or studies of workplace exposure and is not conclusive.
- Parents cannot avoid exposing their children to all EDCs, but there are some practical steps they can take to reduce their exposure.

Further reading

- Breast Cancer UK, ‘Protect your baby’s health’: http://bit.ly/2rQoPCh


