A pathway to improve bereavement care for parents in England after pregnancy or baby loss

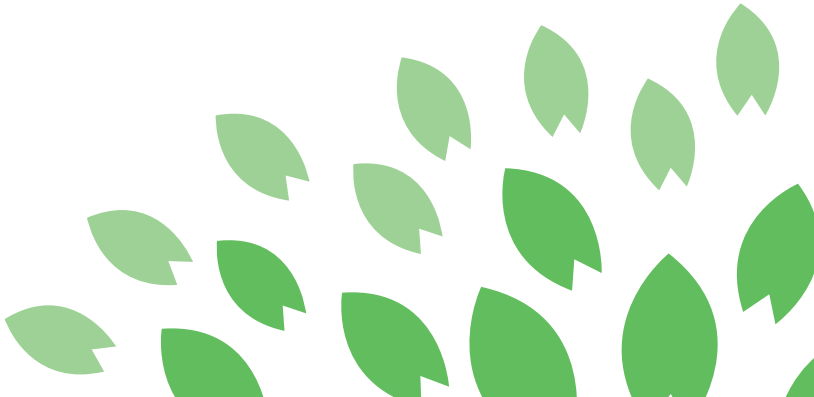
national bereavement care pathway
for pregnancy and baby loss

Neonatal Death

Full Guidance Document

Our National Bereavement Care Pathway core partners

ARC Antenatal Results & Choices
Bliss for babies born premature or sick
IHV Institute of Health Visiting Excellence in Practice
the lullaby trust
MISCARRIAGE ASSOCIATION The knowledge to help
NEONATAL NURSES ASSOCIATION
THE ROYAL COLLEGE OF MIDWIVES
RCGP Royal College of General Practitioners
Royal College of Nursing
Royal College of Obstetricians & Gynaecologists
NHS England
Sands Stillbirth & neonatal death charity



NBCP for use in England from April 2019

About the NBCP

The National Bereavement Care Pathway, led by a multi-agency Core Group of baby-loss charities and professional bodies, has been developed in order to improve bereavement care, and reduce the variability in bereavement care, for families suffering the loss of a baby through miscarriage, ectopic pregnancy and molar pregnancy, termination for fetal anomaly, stillbirth, neonatal death or sudden and unexpected death in infancy up to 12 months.

The project provides a dedicated, evidence-based care pathway with guidance for professionals delivering bereavement care to parents and families. As its name infers, it is a national project, although at this stage its scope is limited to England and not the devolved nations.

This booklet, developed for healthcare professionals working with bereaved families, relates to one of the five pathways which have been piloted in 32 sites and independently evaluated, the report for which can be found on the website below.

For further information, please see www.nbcpathway.org.uk

"Parents don't need protecting; they need the chance to be
parents, provide their child dignity and create memories."

(Quote by bereaved parent, 2017)

Follow-up appointments may take place at home, in the GP's surgery or at the hospital. *Some parents may find it too distressing to go back to the place where their baby died. If this is the case, arrangements should be made for follow-up appointments to take place in another suitable setting or outside normal clinic hours.* Bereaved parents should not have to sit with other mothers with healthy babies or attend an appointment in an antenatal or postnatal clinic.

Discussions at follow up appointments

Parents often have very high expectations of follow-up appointments. They may be hoping for clear answers about why their baby died that will help them make sense of what has happened. If it is not possible to provide these answers, healthcare professionals should acknowledge that this may be difficult for parents and recognise any emotions that parents may feel.

While parents should be told the purpose of an appointment or visit, it is always important to avoid imposing a set agenda and to respond to the woman's and (where applicable) her partner's needs. Some examples of things parents may want from follow-up appointments may include:

- To ask questions about what has happened and to check their understanding of the information they were given at the hospital.
- To discuss the events surrounding the pregnancy loss or baby's death so that they can clarify and confirm what happened.
- To discuss how they are feeling. It is important to ask parents how they feel and to offer them an opportunity to talk. Grief should not be treated as a mental health concern but parents should also be assessed for mental health problems that may be compounding their grief.
- Help in preparing questions for their consultant or GP.
- Suggestions about dealing with the reactions and questions of other family members (for example, other children, their partner, grandparents, a pregnant relative, etc.), friends and neighbours.
- Information and advice about registration and certification.
- Help with decisions about and arranging a funeral for their baby.
- Advice about sex and contraception.
- To discuss the timing of another pregnancy, their chances of having a live healthy baby and how they can reduce or manage any risks. They may also want to talk about any related implications for any existing children.
- To discuss concerns about coping with anxiety in another pregnancy or the possibility of never having a child.
- Information about local or national support organisations.
- Advice about parental leave and claiming benefit payments.
- Advice about coping with or returning to work, including what to say to colleagues and how to deal with their reactions.
- Advice about bereavement counselling that is available to parents and other family members.
- Referral for further investigations including genetic counselling. If they do not want genetic counselling immediately, they should be told how to access these services at a later date.

At the end of the appointment, parents should be told whom to contact if they have further questions, problems or worries. They should be given a named contact and a telephone number and/or email address for that person. In some cases it may be appropriate to offer another appointment. Also, a written summary of the discussion should be sent to the woman, her GP and to the referring hospital if appropriate. They should also be offered information about relevant local and national support organisations.

Feedback and review

Parent feedback

The majority of bereaved parents want to give feedback about the bereavement care they received when their baby died and feel it is appropriate for them to be sensitively asked about the care they received.

Good feedback mechanisms provide parents with opportunities to inform service improvements and feel listened to. Receiving feedback from parents in a structured and supported way gives room for reflection and learning and also promotes the sharing of best practice.

When parents have had a good experience of care at this often very difficult time, it can be important for the staff who cared for them to know that the care they provided was beneficial.

"We would have liked to have fed back how grateful we were for the time they gave us and how understanding they were." Parent, Sands Survey 2016

Conversely, it may feel difficult to listen to parents who didn't receive optimal care. It is important that staff are supported to do this so that they are able to listen to parents in these circumstances. This feedback allows for reflection and learning and promotes service improvements.

All feedback from parents should be taken as an opportunity to learn and develop bereavement care services.

Before implementing a feedback mechanism for bereaved parents, it is important to have the correct structures, policies and procedures in place to ensure appropriate use of the information collected.

The Perinatal Mortality Review Tool is now fully rolled out and can be accessed here: https://www.npeu.ox.ac.uk/pmrt.

"Preparing the framework or wider infrastructure for receiving feedback is essential to ensure that improvements are made in a sustainable way. Feedback may uncover common themes that need to be addressed, or issues may arise from a smaller number of respondents which provides valuable insight. As well as ensuring an effective feedback mechanism for improvement it is also important to celebrate positive feedback when things are done well." Maternity Bereavement Experience Measure, p8.

Reviewing the death of every baby in a standardised, high quality way is important. There are multiple review processes. Parents should be invited to be involved in all reviews regardless of country, system or specialty. Parents should be offered the opportunity to give their questions, concerns and perspectives of care to the review panel. You need to be flexible about how and when this is done.

The parents' perspective may add to the clinical picture. Understanding what happened may impact the parent's grieving and the narrative they share with family and friends for the rest of their lives. Parents must be informed of review outcomes, whether or not they wanted to be involved in the process.

Emotional support

Ongoing emotional support

The grief experienced by a parent when a baby dies cannot be predicted by the gestation or the type of loss they have experienced. Both immediate and long-term follow-up care and emotional support should be available to all parents who experience a pregnancy loss or the death of a baby.

Good communication between staff and healthcare teams is essential to providing good bereavement care and ensuring appropriate continued emotional support is available.

Policies should be in place to ensure that there are efficient processes for keeping all staff informed (with a woman's consent) about a pregnancy loss, a diagnosis of a fetal anomaly or the death of a baby and any treatment or care that has been received or decided upon. These policies should be developed and agreed to by primary and secondary care staff.

If a woman consents, it is important that her medical notes are appropriately marked to alert all primary and secondary care staff that her baby has died. This is to ensure sensitive communication when contact is made, and flag the need for ongoing emotional support.

Services should be accessible to parents from different backgrounds and systems and standard practices should not discriminate against parents. Services should be flexible so that they can be adapted wherever possible to meet the needs of all parents.

Before leaving the clinical care environment parents should be offered information about the emotional support available to them through their care provider and otherwise.

Staff should flag with families:

- Chaplaincies that should have contacts with religious and spiritual advisers of all local faiths and spiritual organisations.
- A contact to provide ongoing emotional support via the care provider (for example, a bereavement lead or community midwife).
- Counselling services available via the care provider.
- Access to counselling and further support via secondary care (for example, GPs and health visitors).
- National and local support organisations.

Staff should communicate with parents about the difficult emotions they might experience, and reassure them that it is okay and normal to not feel okay. Parents should be reassured that they can be in touch with their healthcare team if they need further support and should be given a contact name and number for this purpose.

The death of a baby will be experienced differently by each parent. There might be recognisable themes, but staff should not make assumptions about how a parents is feeling at any point, or about what they may need in terms of ongoing support.

Mental health

Policies and practices should be in place to offer bereaved parents ongoing follow-up care, further assessment and treatment for mental health problems.

Mental health assessment and treatment should be offered to women as well as their partners, other children and family members (where applicable) after any type of baby loss.

Sufficient time must be available in follow-up appointments with bereaved parents to enquire about their emotional well-being and offer assessments for mental health conditions where necessary.

Good communication is crucial between staff and healthcare teams regarding parents who may be at risk of developing or who have been diagnosed as having mental health problems after a baby loss.

Subsequent pregnancies

Parents should be offered continuity of carers during pregnancies, labour and birth that they experience following a loss. The option of having their notes clearly marked may also help to ensure that parents do not need to explain their situation repeatedly. For example, staff might label parents' notes with the **Sands Teardrop Sticker**.

Ensuring that there is good communication between staff (including across teams and departments) is essential in subsequent pregnancies. All staff who care for bereaved parents in subsequent pregnancies should be well-informed about parents' history so that they can respond sensitively to any anxieties or concerns that parents may express.

Another pregnancy

Parents should feel well supported in any pregnancy following a pregnancy loss and the death of a baby. All staff in primary and secondary care settings seeing bereaved parents before, during and after a pregnancy following a loss must be aware of and acknowledge the potential difficulties and challenges these parents might face.

All staff who care for bereaved parents in subsequent pregnancies should be well-informed about the parent's history so that they can respond sensitively to any anxieties or concerns the parents may express.

Offering parents continuity of carers and the option of having their notes clearly marked (Neonatal Pathway Appendix A11) may help to ensure that parents do not need to explain their situation repeatedly.

If the baby who died had a medical or genetic condition that could affect subsequent babies, the chance of another loss may feel too difficult for some parents to consider. Some parents will decide not to try for another baby for other reasons. Other parents may not be able to conceive again.

It is important to:

- Listen to and acknowledge parents' fears and concerns.
- Support parents to make informed choices around if/when to try for another baby.
- Outline any additional antenatal support offered.
- Be clear about the available support from staff and other organisations.
- Familiarise yourself with the parent's notes.

It is important not to:

- Offer false reassurances to parents about having a healthy baby.
- Minimise parents' previous experiences and current concerns.
- Make assumptions about how a parent might feel at any stage.
- Assume parents attended antenatal classes in previous pregnancies.
- Exclude fathers, partners, family/support individuals.

Pre-conception care

The timing of subsequent pregnancies, the risks involved, concerns about their ability to conceive, sexual difficulties and the chances of having a live, healthy baby may be some of the concerns for parents who are thinking about becoming pregnant again. Parents may need an opportunity to discuss their concerns with healthcare staff before trying to conceive.

Some bereaved parents will want to discuss what, if anything, they can do to prevent another loss.

Having experienced a previous loss, many parents will have been in touch with other bereaved parents and heard about their experiences too. This may increase anxiety around situations that were not relevant to their own experience.

Antenatal care

Antenatal care in subsequent pregnancies may involve offering parents extra antenatal appointments, screening options, scan appointments and/or opportunities to discuss an antenatal care plan and birth preferences. It is important to stress that it will not safeguard against any subsequent loss. If there is a specific condition that doctors are aware of and are screening for extra testing will be part of the patient's care.

Staff should allocate extra time for these appointments. Parents should also be able to bring another support person to attend these appointments with them.

It is crucial that there is good communication between staff providing antenatal care for parents in a subsequent pregnancy so that parents do not have to retell their story if they do not wish to do so.

Some parents may welcome more frequent contact with healthcare staff during subsequent pregnancies and will want all available screening and diagnostic tests. Many parents, however, may not need or want extra care. Parents should have the contact details for a named contact in case they have any concerns.

Some parents may find additional appointments, screening and tests stressful and decline some or all of this care. Staff should explain the reason why parents have been offered additional tests or checks. However, parents' decisions about care should be respected.

Parents should be offered regular contact with staff, emotional support and screening for mental health difficulties.

"She was pregnant… again. What should have been fantastic news filled me with sheer terror. I did not know if I could go through this again." Father

"When I got pregnant after 8 months, I wanted to be delighted but I didn't dare let myself in case all our hopes were dashed again." Mother

It is never possible to predict how individual parents will feel during subsequent pregnancies. For some parents, the main feelings during another pregnancy may be grief, anxiety and distress. These feelings may surface in all subsequent pregnancies.

One of the most important things that staff can offer parents is sensitive support to help them deal with the range of feelings and worries that they have.

Certain stages, events or dates during the pregnancy may be particularly difficult for parents, depending on what happened during the previous pregnancy. For example, parents may be very anxious and distressed in the period leading up to the gestational week or date when the previous baby died or an anomaly was diagnosed. Some parents may feel less frightened after this point if all is well. Other parents may remain fearful until after the new baby is born or sometime after their birth for those who experienced the sudden unexpected death of their baby.

Some parents may worry that they will be unable to love the new baby or that they will be disloyal to the baby or babies who died by loving the new baby.

Parents may also worry about the effects of the fear and anxiety they are feeling on the well-being of this baby. It is important that staff acknowledge the validity of parents' concerns and take them seriously.

In addition to the mother, it is important to ensure that fathers and partners are offered support. Fathers and partners may wish to support the mother and may also want reassurance for themselves. Some fathers and partners may be reluctant to voice their fears in the mother's presence as they are concerned about distressing her. Staff should offer fathers and partners an opportunity to speak with staff on their own.

Some parents may try to protect themselves from feeling overwhelmed by fear and anxiety by distancing themselves from what is happening, either throughout the pregnancy or until the point at which they feel their baby is safe, which can be some time after birth depending on their previous experience.

Some parents may prefer to avoid discussing their emotions or previous loss with staff and try to focus on the practical tasks at hand. Other parents are grateful for opportunities to talk about their feelings and their baby or babies who died. Parents should be encouraged to discuss their feelings about their previous loss(es) with staff and be offered counselling or information about other support available.

It is important not to offer false reassurance as this may increase parents' sense of isolation and prevent them from talking openly about their fears. Staff should also be aware that statistical probabilities may not provide comfort for parents.

"I didn't want to love the baby I was carrying. I was so afraid that she would die as well and I knew I wouldn't be able to cope with the pain." Mother

Place of care

Parents who have a good relationship with staff in a particular hospital may want to return there for their antenatal care.

It is sometimes necessary to rebuild parents' trust. Rebuilding trust may be particularly needed if parents are unhappy about aspects of the care they or their baby received when their baby died.

Some parents may prefer to be cared for in a different hospital, GP or by different members of staff, even if their previous care was good. Parents may fear that traumatic memories will be triggered if they return to the place where their baby died or see staff who had cared for them at that time. Healthcare staff should refer parents to another unit or another consultant if requested.

At the first antenatal visit, each woman should be allocated a named midwife and consultant obstetrician. These practitioners should provide most of the woman's care throughout her pregnancy, birth and the postnatal period. They should also carefully read the woman's notes thoroughly before the first appointment and ask parents if it is okay to refer to the baby who died by name if one has been given. Depending on parents' wishes, it may be appropriate for both the named midwife and consultant to attend some appointments. In the case of sudden unexpected death, parents should be given information about the Care of the Next Infant (CONI) scheme run by the Lullaby Trust and the contact details or a referral to the appropriate health visitor or team.

Labour and birth

This may be the first labour and birth experience for this parent, depending on their previous experience. For other women, the birth of their previous baby may also have been when their baby died.

Staff should be prepared for parents' possible emotional reactions during labour and at the birth. Staff should be available to offer support if needed. Women should be aware that support is always available and know how to access staff members. It is also important that support is offered to any partners or birth supporters who are with the woman.

"I felt disconnected during the labour and just couldn't believe that everything would be OK." Mother

Some parents may be surprised and confused if they experience renewed grief for the baby or babies who have died, have mixed feelings or find life difficult when a healthy baby is born. Some parents may not feel they are able to love this baby immediately and it may take a while before they start to experience these feelings. Some parents may feel guilty if they love their new baby.

"My partner was disconnected during my pregnancy, but now our son is born, his dad looks at him every day and cries. He's a lot more emotional now than I am. This baby has really brought his grief out." Mother

Care in the community

Parents who experienced the sudden and unexpected death of their baby may not feel reassured by the birth of a healthy baby and anxiety may continue for some time after the baby is born. It is important to have structured support in place in the community for these parents.

Staff should offer sensitive support to parents after their baby is born. They should normalise parents' feelings and acknowledge that such feelings are shared by many parents and that they usually pass. If these feelings continue for long periods of time after the baby is born, staff should also offer parents a referral for specialist support.

Primary care staff or support groups may be able to offer parents longer-term support and an opportunity to discuss their ongoing concerns.

Parents may want to discuss how to talk about the baby who died with existing and subsequent siblings.

A few parents who go on to have another pregnancy, may experience the death of another baby. This can be deeply shocking and distressing for the parents and staff who are caring for them. These parents may need additional immediate and long-term support from staff.

Staff care

When health and social care professionals are properly supported to provide high quality bereavement care, working with women and families experiencing the death of their baby can be special and rewarding.

There must be appropriate provision for staff support and training. It is also important that staff recognise they have a professional responsibility to access support and training when they feel they need it.

All staff should be supported practically and emotionally so they feel comfortable, confident and competent in this area of care.

Training

Often healthcare staff are expected to cope with distressing events and highly emotional situations without appropriate education and training. Undergraduate, postgraduate and in-service training and updating in bereavement care should be provided for all staff. Provisions should also be made to ensure that staff can be released for this training.

Training can help staff to feel more confident in the care that they provide and help to reduce staff stress. Support and training are essential to ensure staff well-being and avoid staff burn out.

Bereavement care training can help staff to develop skills in communicating more sensitively and empathetically with parents and increase their awareness of the needs of bereaved parents.

Good training and support for staff improves the quality of bereavement care offered to parents when a baby dies.

Support

There are many reasons why it can be stressful and demanding to care for parents during a pregnancy loss or when a baby dies. These reasons will be individual and may include staff having to manage their own emotions following their own experience(s) of loss; a feeling of professional failure following a baby death and anxiety caused by wanting to 'get it right' knowing this is a difficult time for parents.

To provide parents with high quality, individualised care, staff must be well-supported and have time for breaks; an open and supportive work environment; opportunities to share stories and experiences and scheduled multidisciplinary debriefs and reviews. This applies to all members of staff – at all levels and in all disciplines, including all primary care staff who may have long-term relationships with the family and who may be working in greater isolation. This support for staff should be built into the systems in which they work.

The type and amount of support that staff need can vary depending on the individual and the situation. It is important to have different support options available for members of staff to use as they need.

Stigma and concerns about not appearing to be coping with their job may cause some staff to avoid coordinated professional counselling and this should be offered as a confidential service through the central hospital human resources team.

Managers and senior staff have a duty to provide encouragement, support and training for staff, to watch for signs of strain or difficulty in individuals and within teams and to facilitate discussion between colleagues, teams and centres.

Managers and senior staff should also make sure they themselves get support so they can support their staff.

Self-care

As well as organisational, systemic support structures, individual healthcare professionals also need to be mindful of attending to their own needs. Working long hours, shift work and working in often challenging environments and circumstances means that healthcare professionals need to think about what they need to do to look after themselves. This may include making sure they get enough sleep, eating healthily, exercising, relaxation, booking annual leave, watching a favourite film or spending time with a friend or on a hobby or in green space/outdoors.

Further reading

Please make your suggestions in here – this is a further resources list, (not a reference list).
Please include links to useful online learning, resources, papers, etc.

Notes

nbcp
for pregnancy and baby loss

For more information visit:
nbcpathway.org.uk

Lead organisation and ©:

Sands (Stillbirth & Neonatal Death Charity)
Victoria Charity Centre
11 Belgrave Road
London, SW1V 1RB

Sands (Stillbirth and Neonatal Death Society)
Company Limited by Guarantee Number: 2212082
Charity Registration Number: 299679
Scottish Charity Registration Number: SC042789