Supporting families experiencing pregnancy loss or the death of an unborn baby

The loss of an unborn baby can bring about immense pain and grief for parents and the wider family, including siblings. The quality and equity of provision for parents who experience this loss will vary. In order to try to address this, the National Bereavement Care Pathway (NBCP) for Pregnancy and Baby Loss was launched in 2017 (https://bit.ly/36cs9gE).

Health visitors are an important source of ongoing care and support for bereaved parents. A loss during pregnancy is complex and unique, and can be experienced in very different ways by individual women and their partners. Supporting families at this time can create feelings of inadequacy and anxiety in even the most experienced professionals. None of us are immune to grief and loss, and it is important that we recognise this work as emotionally demanding.

This Good Practice Points (GPP) resource is part of a series of GPPs on loss and bereavement. This GPP covers miscarriage, ectopic and molar pregnancy, termination of pregnancy for foetal anomaly and multifoetal pregnancy reduction (ToPFA) to align with 2 of the 5 pathways in NBCP. This GPP aims to support informed high quality care once a pregnancy loss has already occurred.

NOTE: iHV is currently undertaking an important research study (supported by Health Education England South East – Intellectual Disabilities Programme) to support healthcare professionals (HCP)s in "Delivering Different News" - to promote the sensitive approaches and positive language required to support families in receipt of unexpected and different news in pregnancy, and creating iHV Delivering Different News Champions.

Miscarriage

"I find it very hard to see and be around pregnant women or those with babies. It reminds me of what I have lost – we should have had a baby now – it hurts and makes me envious" (Mother - anonymous)

- Miscarriage is the most common kind of pregnancy loss, affecting around one in four pregnancies.
- Early miscarriage is defined as a pregnancy loss from conception to 13^{+6} weeks gestation.
- Late miscarriage describes a pregnancy loss from 14 – 23^{+6} weeks gestation.

There are many factors that affect the impact of miscarriage, including hopes and expectations for the pregnancy, anxiety after previous loss/es and the physical process. Some parents will have formed a strong prenatal attachment to their baby from the very moment they knew they were pregnant. Miscarriage in the second trimester may be especially shocking, emotionally and physically. There is no right or wrong reaction to miscarriage and some people may not experience the miscarriage as a loss for a wide number of reasons (https://bit.ly/2VgV6Sb).

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The information in this GPP version was created on 07/12/2020.

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Ectopic Pregnancy

"Everyone tells me how lucky I am to be alive. But I've lost my baby and I feel so empty"

(Bereaved parent – courtesy of Miscarriage Association UK)

- Ectopic pregnancies are almost always diagnosed prior to the routine 12-week scan.
- Around 1 in 80 pregnancies will be ectopic.

The physical trauma of major invasive treatment, thoughts of their own mortality, the impact on their future fertility and the sad loss of losing their baby very quickly can be very frightening. There may be an association between surgically-treated ectopic pregnancies and suicide (Farren et al, 2016). Women experiencing ectopic pregnancy often consider the condition to be distinct to miscarriage; great care should be taken with language by professionals.

For more information:

The Ectopic Pregnancy Trust: https://bit.ly/36nsVay

Miscarriage Association - Ectopic pregnancy: https://bit.ly/3qiatYQ

Miscarriage Association - Your feelings after an ectopic pregnancy: https://bit.ly/2KLLs8a

Molar Pregnancy

- 1 in every 600 pregnancies is diagnosed as a molar pregnancy.
- There is a 1 in 7 chance of developing persistent trophoblastic disease (PTD) in women with a "complete mole".
- "Partial moles" are more common and carry a 1 in 200 chance of developing PTD.

A molar pregnancy is where a foetus does not form properly in the womb and a baby doesn't develop. A lump of abnormal cells grows in the womb instead of a healthy foetus. It is likely to be confirmed only after histological examination of pregnancy tissue, following surgical management of miscarriage and there can be a delay in notification. The diagnosis and health implications can be frightening. For many couples it represents a second piece of bad news after the original diagnosis of miscarriage. They may be distressed by the thought of a lengthy follow-up and a delay before trying to conceive again. Care following molar pregnancy is likely to be split between the initial referring hospital and one of the UK specialist follow-up and treatment centres: London, Sheffield or Dundee.

For more information:

Miscarriage Association: https://bit.ly/2Juz8IS

Molar Pregnancy Support and Information: https://bit.ly/2KTPsnk

Termination of pregnancy for foetal anomaly (ToPFA)

"By no means was it the 'easy choice' some people seem to feel it is. It is a choice full of heartbreak and grief"

(Bereaved parent – Courtesy of ARC UK)

Statistics for England and Wales identify 3,183 ToPFAs were carried out in 2019 and suggest this is an under-report of at least 40% (DHSC, 2020). The number of ToPFAs may be comparable or even exceed the number of stillbirths every year.

- Terminations of pregnancy for foetal anomaly might be undertaken at any stage of pregnancy – few are undertaken prior to 12 weeks.
- When required at more than 21 weeks$^{+6\ days}$, a foeticide procedure using Potassium Chloride is used to avoid a live birth.

Empathetic care is crucial for parents who fear being judged for their decision:

- Parents may experience additional distress and trauma if they perceive professionals to be unsupportive or disapproving of their decision to terminate the pregnancy.
- Professionals should reassure parents that complete confidentiality will be maintained as they may wish to keep their decision private (even from other family members).

For more information:

Antenatal Results and Choices: providing specialised bereavement services for women and couples who have experienced ToPFA: https://bit.ly/3fORRuU

Healthtalk.org: providing videos of parents sharing experiences: https://bit.ly/3lpufxS

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Selective and multifoetal pregnancy reduction

"The emotions that swamped us over the next few days were completely overwhelming. How does one integrate the feeling of grief for one baby with the feeling of joy for the other? After all we had only wanted one healthy baby and we still had that. So why did we feel so terrible?"

(Bereaved parent – courtesy of SANDS)

- Women having a multiple pregnancy may be offered selective reduction if one of their babies is diagnosed with a foetal anomaly. This procedure carries risks to both foetuses and can be an extremely difficult and painful decision to have to make.
- In pregnancies with three or more foetuses the risks of miscarriage, stillbirth and lifelong disability increase with each additional foetus. Parents may be advised to consider reducing the number of foetuses (multifoetal reduction) in the absence of foetal anomaly.
- Empathetic care is crucial, for example, parents who have conceived following fertility treatment may decide to terminate one or more foetuses after a struggle to become pregnant. After the surviving baby/babies are born, professionals should be aware that parents may also experience immediate and/ or long-term grief, and ongoing support and care may be required.

For more information:

The Multiple Births Foundation: https://bit.ly/3obkDbT

Twins Trust: https://bit.ly/2JChBOQ

Subsequent pregnancy following a pregnancy loss

"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."

(Bereaved parent – courtesy of SANDS)

"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."

(Bereaved father – courtesy of SANDS)

- It is not possible to predict how individual parents will feel during subsequent pregnancies. Providing sensitive support which acknowledges and validates parents' concerns and takes them seriously is important. Alongside supporting women, it is important to ensure that fathers and partners are also offered support. Some fathers and partners may be reluctant to voice their fears in their pregnant partner's presence so, if possible, create an opportunity for them to speak on their own. Sensitive support will also be needed after the baby is born to normalise parents' feelings and acknowledge that these usually pass. If the feelings continue for long periods of time after the baby is born, a referral for specialist support should be considered.

Good Practice Points – What can HVs do?

"For me the simple things make a huge difference. Being listened to. Eye contact and someone sitting beside me – communicating they have time for me."

(Bereaved parent - (NBCP))

"Why didn't anyone check in with me afterwards? I had been on their records and yet there was no call the week after to see how I was doing. There was no information of what to expect or where to get help."

(Bereaved parent - (NBCP))

Reach out and offer support

- On receiving information about a pregnancy loss, contact the family to tell them that you are there and offer a face-to-face contact. When you are contacting the family by telephone, ensure that background noise and interruptions are avoided. Start conversations by expressing compassion:
  - "I'm sorry this has happened to you"
  - "I'm so sorry to hear about your baby".
- Parents may feel shocked and may find it difficult to understand information or think clearly - speak clearly and use simple language. Cultural norms or personal circumstances may affect a parent's readiness to engage, ask questions or express their feelings or wishes.
- When visiting, sensitively and jointly agree the time available for the contact. This creates a safe environment where parents know what they can expect, and it avoids the interaction ending abruptly.

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Be client-led in language used

- Many people will consider themselves parents from the time they discover they are pregnant while others will not. It is important for those who do identify themselves as parents to have this recognised. Check the words they prefer to use.
- Explore with the parents how they wish to refer to their baby. If the baby has been given a name always use their name.
- All communication with parents experiencing a pregnancy loss must be empathic, sensitive, non-judgemental and parent-led:
    - Use warm, open body language by sitting near parents, facing them, making eye contact and using touch if appropriate.
    - If communicating over the telephone be mindful of your tone and background noise.

  It is okay to show emotion, but the parents should not feel they need to look after your feelings.

Be aware of culture and beliefs

- Recognise that parents come from a wide range of cultural and spiritual backgrounds, so check with parents to gain understanding of their beliefs regarding loss – do not make assumptions.
- In some cultures, perinatal grief is not recognised, and parents will be expected to continue as if nothing has happened. There may also be stigma and shame around loss that could result in further trauma and isolation.

Listening and validating

- Allow parents to talk through their feelings, tell their story or sit in silence. Giving your time is acknowledgement of their loss.
- Many professionals feel inadequate when discussing grief, and worry that they will say the wrong thing – avoid making any statements related to trying to make parents feel better.
- Some parents may wish to share scan pictures of their unborn baby with you. Others may want to create a lasting memorial and may welcome discussing this with you.
- Communicate with women/couples about the difficult emotions they may experience and reassure them that it is okay and normal to not feel okay.
- Acknowledge that the parent couple may each experience the loss differently. Whatever they experience, it is important that they know that there is no right or wrong way to feel or grieve.
- Each parent's experience of pregnancy loss will be unique. Some parents will find written resources and access to other sources of support helpful – signpost to these as appropriate. You may wish to consider The Good Grief Trust: https://bit.ly/39vWtoD
- Reassure that they can be in touch with their health visiting team if they need further support and offer a contact name and number for this purpose.

Support mental health

- Some parents may relive moments associated with the loss, again and again, as they try to process what happened. It may be appropriate to arrange for parents to be seen by the obstetrics or gynaecology team so that they can talk through the experience with them.
- While the emotional impact of pregnancy loss can be difficult to accept, grief is a normal process following loss. There are many ways to express grief and these vary from person to person and can change over time. Parents can be supported to find their own ways of grieving that they find helpful.
- It can be helpful to explain the symptoms of depression, anxiety and post-traumatic stress disorder (PTSD). There may be a need for further assessment and formal treatment. There is an increased risk of suicide following pregnancy loss (Weng et al, 2018) and any suicidal ideation should prompt immediate assessment.
- NICE recommends: Offer advice and support to women who have had a traumatic birth or miscarriage and wish to talk about their experience. Take into account the effect on the partner and encourage them to accept support from family and friends. Offer women who have post-traumatic stress disorder, which has resulted from a traumatic birth, miscarriage, stillbirth or neonatal death, a high-intensity psychological intervention. Do not offer single-session high-intensity psychological interventions with an explicit focus on 'reliving' the trauma to women who have a traumatic birth. (NICE, 2014).

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- PTSD can occur in men and women as a result of complications of pregnancy and birth. NICE NG116 recommends professionals are alert to, and observe for, signs of PTSD (NICE, 2018).

- The brief screening questions below are an example of how questions can be framed (Prins et al, 2015). If there are concerns, the parent should be referred for full assessment.

  In the past month, have you...

  1. Had nightmares about the event(s) or thought about the event(s) when you did not want to?
     YES / NO
  2. Tried hard not to think about the event(s) or went out of your way to avoid situations that reminded you of the event(s)?
     YES / NO
  3. Been constantly on guard, watchful, or easily startled?
     YES / NO
  4. Felt numb or detached from people, activities, or your surroundings?
     YES/NO
  5. Felt guilty or unable to stop blaming yourself or others for the event(s) or any problems the event(s) may have caused?
     YES / NO

Practitioner wellbeing when offering support

It is important for health visitors to seek support for themselves and to pay attention to their own thoughts and feelings. Seeking out supervision that has a space for you to focus on how the work is affecting you is a good way to do this, and is an important aspect of good practice.

More information for HVs:

Two e-learning modules for Bereavement Care after Pregnancy Loss or Baby Death are available on the e-LfH platform at: https://bit.ly/3gcsFNF

Further e-learning from the Miscarriage Association at: https://bit.ly/39xkAmY

The National Bereavement Care Pathway (NBCP) provides specific materials for HCPs:

- Miscarriage Bereavement Care Pathway: https://bit.ly/39CtKyB
- Termination of Pregnancy for Foetal Anomaly (ToPFA) Bereavement Care Pathway: https://bit.ly/33yuS2f

Brene Brown film clip explores the differences between empathy and sympathy: https://bit.ly/3lsnsn6

The Good Grief Trust has developed a range of videos for professionals: https://bit.ly/39tq5Ty

References

DHSC (2020). Summary information from the abortion notification forms returned to the Chief Medical Officers of England and Wales. January to December 2019.

Farren, J, Jalmbrant, M, Ameye, L, Joash, K, Mitchell-Jones, N. Tapp, S, Timmerman, D, & Bourne, T. (2016). Post-traumatic stress, anxiety and depression following miscarriage or ectopic pregnancy: a prospective cohort study. BMJ open, 6(11), e011864 - https://bit.ly/38FgFlo

Miscarriage Association: https://bit.ly/2VgV6Sb National Bereavement Care Pathway - https://nbcpathway.org.uk/

National Bereavement Care Pathway: https://bit.ly/36cs9gE

NICE (NG116) Published date: 05 December 2018, Post-traumatic stress disorder - https://bit.ly/31ZQoNm

NICE (CG192) Published date: 17 December 2014, Antenatal and postnatal mental health: clinical management and service guidance: https://bit.ly/32YKNq7

Prins, A., Bovin, M. J., Kimerling, R., Kaloupek, D. G., Marx, B. P., Pless Kaiser, A., & Schnurr, P. P. (2015). The Primary Care PTSD Screen for DSM-5 (PC-PTSD-5) - https://bit.ly/3iLjRRc

Weng, S-C, Chang, J-C, Yeh, M-K, Wang, S-M, Lee, C-S, Chen, Y-H (2018). Do stillbirth, miscarriage, and termination of pregnancy increase risks of attempted and completed suicide within a year? A population-based nested case–control study. British Journal of Gynaecology. 125: 983– 990.

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