Caring for patients with second trimester loss: a good practice guide

Developed by the Miscarriage Association

"When they told me they couldn't find a heartbeat, I think my heart stopped too. I was full of the joys of being pregnant, only to feel I had been hit by a train head on."

From a medical perspective, miscarriage is a common and generally minor complication of pregnancy but for patients and their partners it can be very distressing, shocking and frightening, whatever the gestation.

This guide focuses on second trimester miscarriage, defined here as pregnancy loss between 14^{+0} and 23^{+6} weeks' gestation. Losses at these gestations are far less common than those in the first trimester and their impact – psychological and physical - may be even greater.

Whatever your role in caring for someone with second trimester loss, your approach can make a positive difference to their experience, even in the most distressing of circumstances.

We spoke to women[1] and health professionals about what helps and what makes things harder.

Women told us that they needed clear information about what was happening and what to expect. They valued kindness and respect for themselves, their partners and their babies.

Health professionals told us that they wanted to give the best care possible wherever women were treated – in gynaecology or maternity departments – but that women could not necessarily choose their place of care.

We share their input and our recommendations in the following pages.

[1] All but one of those we spoke to identified themselves as women, but we recognise that some patients will not identify as such. The other respondent was a male partner. We note too that while we mention partners in this guide, some patients will not have a partner and some may have a different supporter in this journey who may also be affected by the loss.

"I had some spotting at 16 weeks. I read online that this can be normal but I was worried and went to get it checked out."

First signs – or none

Women with second trimester loss may present with any of a range of expectations, concerns and emotions:

- attending their 20-week scan:
  - feeling positive, looking forward to seeing their baby
  - feeling anxious because of a previous loss or losses

- a non-routine appointment, perhaps referred by the GP or from A&E, or invited in by their midwife:
  - feeling anxious because of a previous loss or losses and seeking reassurance
  - feeling anxious, perhaps very anxious, due to spotting, bleeding, pain or loss of fluid

- in the process of miscarrying or labour, or having already delivered
  - feeling very distressed, shocked and/or frightened.

The examination

In any of the situations above, including excited anticipation, emotions can be high, and every element of the assessment may be followed closely. Women tell us that they are often acutely aware of long silences or of the facial expressions or body language of whoever is examining them.

Good communication, clarity, honesty and **sensitivity** can help everyone involved.

- If you are conducting a scan, set the scene by telling the woman that you will be quiet for a few minutes until you can get a clear image.

- If the scan shows a pregnancy smaller than dates, explain what this might mean.

- If you need to consult a colleague, tell the woman what you are doing/where you are going and why.

- Whatever the examination or tests, give any clear, positive results (e.g. the baby's heartbeat) and consider carefully how to deliver news that isn't good.

- Bear in mind that shock and distress can make it difficult for people to understand and digest information. You may need to repeat it.

- If you cannot give definite answers, recognise and empathise with how difficult it can be to live with uncertainty. If there is a chance that the woman may go on to miscarry or deliver, provide information 'in case this happens' so that she can be prepared practically and emotionally. See more detail under **Next steps**.

Delivering difficult or unexpected news

It is never easy to inform a woman or couple that their baby has no heartbeat, or that their baby has died or is likely to die. This is difficult enough in the first trimester but because second trimester loss is so much less common, it is also more unexpected, both for the woman or couple and for anyone caring for them.

This is especially the case if there was no indication that anything was wrong. Even if there were worrying signs or symptoms, there will likely have been hope as well as anxiety. In all of those circumstances, the diagnosis is likely to be very shocking as well as distressing. It may be met with disbelief.

Women who are already in the process of miscarrying or are in labour may not always realise that this is what is happening. They may hope that the situation isn't as bad as it seems, that something can perhaps be done to stop the process. They too may be very shocked to be told that sadly, their baby has died.

Women who arrive having already delivered their baby, as Rachel did (click for video), are only too aware of what has happened. Thay may still be very shocked by what they have been through and perhaps still bleeding heavily and in pain.

If one or more babies in a multiple pregnancy has died but one or more is still viable, the woman or couple may have very confused and even conflicting feelings, including grief and hope. It is important to be sensitive to the fact that the continuing pregnancy or pregnancies may still be at risk and even if continuing, may be no compensation for the baby or babies that died.

We talk more about delivering difficult news in this good practice guide. We also strongly recommend the UK consensus guidelines for the delivery of unexpected news in obstetric ultrasound: The ASCKS Framework

Think about your language

When it comes to pregnancy loss, women and their partners are often acutely sensitive to the words you use, finding some terms, such as *products of conception*, *blighted ovum* and *incompetent cervix* particularly distressing.

The words that you use to refer to their pregnancy – *fetus, baby, pregnancy* – may or may not feel right for them.

The term that you use for second trimester loss can itself be problematic. For some, the word 'miscarriage' does not reflect – or prepare them for - the physical experience of labour and birth. Some feel that it makes their loss sound less significant.

When we asked women how they would prefer their experience to be described, the clear preference included the word 'loss', including 'second trimester loss'.

A smaller but significant number wanted their loss to be called 'stillbirth', even though they knew this was not the legal definition:

> **"By all accounts I gave birth to a still baby but didn't technically have a stillbirth. If I say it was a stillbirth, it's not technically true... What I feel best describes what I went through isn't accurate."** [2]

We suggest that as far as possible, you listen to the words that women and partners use when in your care and take your lead from them, mirroring their language.

- Most (but not all) women think of their pregnancy as a baby. Most (but not all) prefer you to refer to it that way. Some may not be sure what word to use.

- If you're not sure what term to use, and have no clues from the woman or couple, start with the word 'baby' and be sensitive to their reaction. Perhaps ask what she or they would prefer.

- Use everyday lay language when you can but when you use medical terminology, be prepared to explain it. Your patient may be too embarrassed to ask what you mean.

- Always keep in mind that shock and distress can make it difficult for people to understand and digest information. You may need to repeat it.

Next steps

> **"I had never experienced anything like this before. I needed things explained clearly and [in a way that was] easy to understand."**

> **"A lot was happening and said at me and I - my mind had just switched off. I think it was mainly my husband or my sister trying to listen to what's going to happen next, but I was just, like, out of it by then."**

[2] You can see more comments from our survey respondents here.

Women emphasised the need for clear **information** throughout their care, both to help them manage the immediate situation and to prepare emotionally and practically as their situation unfolded. They highlighted the need for information:

- about what is happening now:
  - some women may not realise that they are in active labour or that the loss is inevitable
  - if there is any uncertainty about the diagnosis or outcome

- about management options, if the diagnosis is clear:
  - clear information, sensitively given, perhaps in stages
  - allowing time for questions and time to make decisions
  - written information where possible
  - some women will be shocked that they will need to go through labour and delivery: they may expect to be treated surgically
  - some women will not want labour induced and would rather wait for nature to take its course

- about possible or likely timelines:
  - between assessment and diagnosis
  - between signs/symptoms and loss (as in Rachel's case) or
  - between diagnosis and the baby dying (as in Zainab's case)
    - these days or weeks of uncertainty, of being 'in limbo', can be very difficult to bear

- about what might happen while awaiting further assessment or management:
  - the possibility of increased bleeding, spontaneous labour or delivery
  - practical advice on managing pain and bleeding (medication, pads)
  - where the loss or delivery might happen, e.g. while she is on the toilet
  - information about what she might see, and what she might do with the baby or fetus
  - information about when and where to access help or further care, with clear contact details.

"The baby's heartbeat was normal and they confirmed that my cervix was closed but even at this point, even though the bleeding was heavier, they didn't really talk about the miscarriage risk or how they might manage the situation if it was a miscarriage. I went away not reassured and looking back, I wish I'd asked more questions."

Labour and birth

It is important to provide information about the process of labour and birth. While some women with a second trimester loss may have already had a live birth, or a stillbirth, the experience of loss before 24 weeks may be very different. A woman who has not had a

previous birth may know very little about what to expect even in a normal term delivery, especially as she will not have been to antenatal classes.

The care, support and information that you and your colleagues provide can make all the difference in helping women through. We suggest the following:

- If the woman chooses to go home rather than be induced, check if she plans to come into hospital once she is in labour or if she wishes to give birth at home, and provide what information and advice you can.

- Prepare the woman and partner for what to expect during labour and delivery, including information about pain relief options.

- Ask the woman or couple whether they might like to see or hold their baby after the birth or at a later time. Offer:
    - to tell them more about what the baby might look like, the possibility of their skin being very fragile or discoloured
    - to wrap the baby before bringing him or her to them
    - the option of using a cold cot if they want to keep the baby with them or see them at a later time.

- Offer to take a photograph of their baby, and to keep it in the woman's notes if she would prefer that. If the baby's condition allows you to take handprints or footprints, ask the woman or couple if they would like this.

- Accept that they may not want any of these options and reassure them that this is fine. But for some, a little encouragement and reassurance may make a real difference:

"I was encouraged to hold and cuddle my son, I'm so glad they did this, I'm so glad they made sure I knew this was ok.

"Of course I wanted to hold him but I was scared, scared of how it would feel, scared that I would somehow break his tiny body but they made me feel that it would be ok, and it was."

Seeking consent

You may be tasked with providing information and seeking consent with regard to further investigations and the disposal of the baby's remains. These can be very difficult and distressing conversations for the patient and for you too.

"When you are in such a cloud of deep grief you simply cannot retain information, think clearly or make decisions. It was helpful to have

24hrs between the loss and the start of the physical process to also think about all these decisions as a couple."

Investigations

Even though women and partners may want very much to know the cause of their loss, they may not be ready to talk about investigations and tests when you suggest it. It should be possible to offer them options for when to have this discussion – if possible, before the process of labour. In the meantime, you might offer to provide just a sentence or two to outline what investigations might be offered.

- Ensure that you know what investigations are likely to be offered and how best to describe these.

- Always explain that having investigations does not necessarily mean that a cause for the loss will be found, but that it may rule out some possible causes.

- Allow time for the woman or couple to consider their options and always respect their decision.

- Be aware that most people will imagine that a post-mortem or autopsy is always a full post-mortem, with incisions, and they may find this very distressing. It is important to explain other options so that they are fully informed.
    - We describe all these options briefly on page 8 of this leaflet. And you might find it helpful to see the additional information we provide for woman and couples on this web page.

"We finally agreed on an external examination and a look at the chromosomes. The results were normal, which we found reassuring even though we still had no explanation as to why we lost our baby."

- Inform the woman or couple of the likely timescales for the return of their baby after a post-mortem and how and when the results will be communicated; and be as realistic as possible about these. Timescales may be far greater than they – or you - expect.

Disposal

"We struggled with making decisions as this wasn't ever anything that you would think to prepare for. We decided on individual cremation so we could take her home."

There is nothing easy about talking with patients about what they want to happen to the remains of their baby or pregnancy. Women and their partners are almost certainly very distressed already and now you are asking them to make choices that they probably never dreamed they would be faced with. You may worry that whatever you say will cause them even more distress.

The key things to consider are:

- making sure your knowledge about options is up to date:
    - your hospital's provision and national guidance
    - the option to take the remains home and/or to make private arrangements
    - their choice not to make a decision

- Thinking about the timing of the conversation
    - they may not be ready to think about this then or at all
    - the possibility of just providing written information
    - the timeline for making a decision and the option not to decide at all

There is more guidance on having these conversations in this good practice guide and you might also find this video helpful.

In summary

Whatever your role, caring for patients with second trimester loss can be difficult and sometimes challenging, but it can also be meaningful and fulfilling. Good listening, clear and sensitively worded information, and thoughtful and compassionate care can make even the most distressing circumstances more bearable for women and couples.

Here is one patient's feedback on the care she had after her loss at 17 weeks' gestation.

> **"We were in hospital for three days in the bereavement suites. The midwives were incredible.**
>
> **"I had gas and air but other pain relief was available.**
>
> **"They had cold cots so our daughter could stay with us as long as we wanted.**
>
> **"They helped us make memories - hand and footprints, photos etc.**

"They treated her with so much care and respect. They were so kind and caring with us.

"It was a traumatic and devastating experience but we had such good care that we also have very precious and cherished memories of our time in hospital."

****

Got more time?

These additional resources may be helpful.

Take a look at the Miscarriage Association's patient information leaflets Your feelings after miscarriage and Second trimester loss: late miscarriage.

You might also find it useful to see the online information we provide for people affected by second trimester loss.

View the resources and references list in our e-learning package.

Have a look at this support resource for parents experiencing second trimester loss.

Read this BJOG paper: Parents' experiences of care following the loss of a baby at the margins between miscarriage, stillbirth and neonatal death: a UK qualitative study.

Take a look at the guidance about how to assess signs of life following birth in the second trimester of pregnancy.

Consider your needs too

In addition to training, identify your sources of support. The most likely of these will be your peers:

- in your hospital/Trust:
    - individually, informally
    - in staff meetings, training sessions and/or clinical supervision
- peers from other hospitals or clinics:
    - individually, informally

    - through existing or developing networks like the Association of Early Pregnancy Units
    - joining one of the monthly 'Professional Pause' sessions[3] hosted by the Miscarriage Association and the Ectopic Pregnancy Trust.
- It's worth considering that your peers may have similar concerns and might also benefit from talking about these issues together.

You might also consider:

- your partner, if you have one, or a trusted friend
- talking to us at the Miscarriage Association in strict confidence.

And remember:

Pregnancy loss is never easy – for the woman or couple involved or for the staff who are tasked with looking after them. You may not get it right for everyone, but patients will always remember your care, kindness and compassion.

[3] These sessions offer a safe online discussion and learning space to share experiences and reflect on challenging situations in order to support your practice, while also considering your needs. Contact helen@miscarriageassociation.org.uk for details.