

Discussing management of miscarriage¹: a good practice guide Developed by the Miscarriage Association

"I wish they had asked how I was feeling. Everything was focused on what happened next but I was feeling too raw to think ahead. It was devastating – I was absolutely distraught."

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

This can be even more so when the physical process of loss has not yet happened and women are faced with making a choice between options for management. Your approach can make a positive difference to the patient's experience.

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

Women told us that they wanted clear and honest information, presented with kindness, sensitivity and acknowledgement of the emotional impact of miscarriage. They also talked about the importance of overall care at this time.

Health professionals told us that they sometimes found it difficult to have these conversations, particularly when patients were already very distressed. They could feel pressured by time constraints and the needs of other patients.

We look at all these points below. You may also find it useful to have a look at our films on <u>scanning in pregnancy</u> and on talking to patients about the <u>sensitive disposal of pregnancy</u> <u>remains</u> as these are often linked in practice.

The context

After miscarriage (or ectopic or molar pregnancy) has been confirmed, you may need to talk to the woman and her partner about management options.

¹ While we talk primarily about miscarriage here, the same principles apply to ectopic or molar pregnancy.

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"Calm silence doesn't mean I'm OK with it. It can be shock, still processing it or internal chaos."

Key things to think about are:

- The woman's (and maybe her partner's) emotional state:
 - o shock (no idea anything was wrong) and disbelief
 - o prepared (due to symptoms or previous scan) but still upset
 - o extremely distressed
 - o no obvious show of distress
 - o relieved
 - o angry
- When's the best time for the conversation? Does it have to be now? If so, is this for:
 - clinical reasons?
 - o administrative reasons (record-keeping, guidelines, time pressure)?
 - personal reasons (your fatigue, wanting to get it over with)?
- Can they actually cope with it now?
 - Can you offer alternatives? Perhaps a first brief conversation about what the next steps are and the option of having that discussion in an hour or so or later that day, or another day.
 - Consider asking if the woman/couple would value having written information before the conversation or after.

Consider how she (or they) might be feeling – be sensitive and compassionate

For most women (and their partners), miscarriage means the loss of a baby, whatever the gestation. They want you to recognise and understand the emotional impact of their loss, showing empathy and acceptance of whatever they are feeling.

Women (and their partners) may also find it very distressing to have to make a decision at all about their next steps, as all options involve the final loss of their baby.

"I started to realise what the three options really meant. I would essentially have to bleed everything out of me, but this could take 2 or 3 weeks to happen; I could have some medication to make this happen faster; or I would have to have it surgically removed. None of these options appealed to me at all."

Think about your 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.
- If you're not sure what term to use, mirror what she uses (baby, fetus, pregnancy) or ask her what she'd prefer.
- Try not to minimise the loss. Referring to it as a 'just a heavy period', 'back luck' or saying 'at least you know you can conceive' can actually increase distress.
- You many need to explain medical terminology that she has heard or read elsewhere.
- Do not use the term 'abortion' (or threatened, missed or incomplete abortion) to describe miscarriage.
- Women also said they found terms like 'products', 'blighted ovum' 'scrape' and 'vacuumed out' hurtful and upsetting.

"I discussed this with my colleagues. We agreed that different women feel differently, and find different things helpful at different times. (We should) be guided by them rather than trying to deliver the perfect one-liner."

Provide clear information about each option and time for questions

"Thank you to the nurses for their kindness and sensitivity, listening to my concerns, never making me feel silly and explaining all options with compassion."

- In the film Emily says "I was all over the place" and Catherine says, "that's when you go a bit numb and don't take anything more in". Women who are feeling distressed and shocked may find it hard to process information and make a decision.
- Give clear, accurate and unbiased information about each option and an explanation as to why one or more might not be possible or advisable (e.g. for clinical reasons).
- It's inappropriate to over-emphasise the risks or disadvantages of one option while minimising those of a different option.
- Women told us that they wanted more information about what each option means in practice, to help them make an informed choice.
- Avoid inaccurate information ('like a heavy period') or vague/confusing information ('torrential bleeding').

 If she is likely to miscarry at home, explain that she may have strong to severe pain and heavy bleeding which may contain large clots; and that she might see something that is recognisable as her baby. If you do not provide pain medication, advise her about over the counter options, such as co-codamol and also suggest that she buy sanitary pads suitable for a heavy flow.

"For medical management at home we give codeine phosphate and an anti-emetic."

- You may feel as if you are scaring her by being honest about possible pain and bleeding. But being clear about what might happen will help women decide and prepare. Nobody is going to make a complaint if the pain and bleeding aren't as bad as you said they might be.
- Provide written information for women to take away and read yours and/or ours.

Important practicalities

"The room where we spoke was awful and I can still picture the mess and food crumbs."

Some practical aspects may be out of your control, but it can help to show you understand how hard it can be.

Time. Women and their partners need time to talk and understand what is happening next both before and during your conversation. They don't want to wait too long but neither do they want to be rushed. If possible, turn your bleep off and make sure there is time to answer questions.

Place. Many women remember the place where they had this conversation for a long time afterwards. Talk to the woman when she is dressed and sitting down. Use a clean, tidy, private room (if possible without pregnancy or baby posters on the walls).

It can be very difficult to wait in a room where lots of pregnant women are waiting for a scan and couples who have had good news are leaving. If possible, find the woman and her partner a private space to wait. As Catherine notes in the film, this can help those waiting too.

Other aspects of care

It is important to show acknowledgement and understanding of distress throughout the provision of care.

"I wish the staff in day surgery had considered the operation I was in for. I wasn't just there for a bunion removal so it wasn't routine to us, it was the removal of our baby and all the emotions behind it."

Be aware that the practicalities of day surgery can be harder for women waiting for management procedures:

- they may have to wait without food and water while still feeling pregnancy nausea
- they may find it very difficult if their partners are not allowed to wait with them
- they may be on a ward with patients having terminations and some women find this upsetting
- surgery consent forms that require an answer to the question "are you or could you be pregnant" are almost certain to cause distress. Staff completing the form should know that the woman is having surgical management of miscarriage and fill in the appropriate answer if that is possible.

Be careful of the language you use during follow up...

"The consultant scanned me after the delivery and said 'you're completely empty' with a big smile, like it's what I wanted to hear".

The procedure going well medically still means the woman has lost her baby.

Consider how you might re-phrase the following comment made to a woman who returned for a scan after conservative management:

"That's fine – all the products have passed."

... and remember that body language is also important.

Provide information about what happens next

Discussion about the disposal of pregnancy remains often happens at the same time as conversations about management options. You may find it helpful to have a look at our training materials on <u>talking about the sensitive disposal of pregnancy remains.</u>

Make sure the woman (and her partner) understand **what to expect** in the weeks during and after management.

Provide information about support and counselling options:

- within the hospital: bereavement support staff, chaplaincy etc
- beyond the hospital: local or national support and counselling services
- <u>The Miscarriage Association</u> provides support and information via our website, phone, email and online groups. Pass on our information with a contact card (we can provide you with these)

Got more time?

You might find these resources helpful.

Positive patient feedback on her care, via Patient Opinion

The Royal College of Obstetricians and Gynaecologists training Listening to women and compassionate care

Miscarriage Association leaflets: Management of miscarriage: your options and Your feelings after miscarriage.

The Miscarriage Association is a resource for you as well as for your patients. If you have any questions or would like to talk anything through, please do <u>get in touch</u>.

Consider your needs too

Talking to patients about management of miscarriage can be difficult and distressing – for them, of course, but also for you. Whether or not you have done the scan that has confirmed a pregnancy loss, you are probably delivering a lot of information to someone who is already in distress and that can be upsetting for you too.

"It's difficult knowing how to phrase words, having confidence in my own knowledge to be able to sufficiently answer questions, and not feeling I have the experience to be able to clearly explain what the patient should expect (physical symptoms, emotional features)."

The following suggestions might help.

Identify the difficulties

The context:

- if this is your first encounter with this patient
- where the conversation takes place
- time pressure: the need to give the information and get a decision
- needing also to talk to the patient about disposal

Particular situations that are difficult or distressing:

- where the patient (and perhaps her partner too) is still reeling from confirmation of her loss
- if she doubts the diagnosis and is not ready to make a decision
- anxiety that you might be increasing her/their distress
- a patient you know from previous loss/es
- a patient or loss that you identify with due to your own experience
- your own views and values on the significance of some losses.
- fatigue physical and emotional.

Identify your sources of support ...

Your most likely source of support 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 <u>Association of Early</u> <u>Pregnancy Units</u>
 - joining one of the monthly 'Professional Pause' sessions² hosted by the Miscarriage Association and the Ectopic Pregnancy Trust.

² 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.

You might also consider:

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

... and make use of them

It's one thing to know where you can find support. It's another thing to do something about it. It's worth considering that your peers may have similar concerns and might also benefit from talking about these issues together.

And finally

Miscarriage 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.

"The nurse gave us five minutes to ourselves immediately after the scan; she had a box of tissues ready (important!!), she actually seemed sad for our loss rather than clinically impartial. She must see it all the time but for us it was a life-changing event and we appreciated her sincere sympathy."