Talking about sensitive disposal of pregnancy remains: good practice guide

Developed by the Miscarriage Association

> **"I discussed with nurses what I could do with the baby and they were incredibly sympathetic and caring with their words, their tone and their time. They were also knowledgeable about what I could do with it, about bringing it back to the hospital."**

Talking to patients about the disposal of pregnancy remains can be a difficult and daunting task.

Women and their partners may already be distressed. They may have already had to make difficult decisions about how the loss is managed and are perhaps anxious about what is to come.

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. And you may also find the topic of disposal, and the words that describe it, very difficult, perhaps upsetting and even distasteful.

But you have the potential to make a positive difference at a difficult time.

We asked patients and health professionals what helps and what makes things more difficult.

Women told us that they wanted a gentle introduction to the topic so they could choose when (or whether) to have information, verbally and/or in writing. They wanted sensitivity and honesty and time to think.

Health professionals told us that they sometimes found it difficult and upsetting to have these conversations, particularly when patients were already very distressed.

We look at all these points below. You may also find it useful to have a look at our films on scanning in pregnancy and on talking to patients about management of miscarriage, as these are often linked in practice.

Make sure your knowledge is up to date

You need to know exactly what your hospital/Trust offers.

> **"I need to know what sensitive disposal means, I need to be told about what I can do. I need to know if I can see it if I want to… to know how I will be given my baby back… to know what things I can do with it."**

For sensitive disposal*:

- burial or cremation, individual or collective
- whether there are any gestational limits to what is offered, or
- whether options depend on what is visible to the eye ('identifiable fetal tissue')
- whether there are any costs to the patient
- taking the remains home if they want (***it is absolutely legal***) and whether suitable containers are provided
- what the timeframe is for making a decision
- what happens to the remains if patients don't or choose not to make a decision. This may be disposal as clinical waste (except in Scotland).

** This should at minimum meet the standards set out by the Human Tissue Authority in England & Wales; or by the Scottish Government. The Royal College of Nursing has also published guidance for those working in England, Wales and Northern Ireland.*

Women and their partners considering cremation may ask about ashes. It is helpful if you know that:

- there is much less of what we call 'ashes' at small gestations, though this varies with the temperature of the cremator used
- the ashes collected may be all or mainly those of the container in which the remains are cremated, but these may still hold real value and significance for the parents
- in cases of collective cremation, where several sets of remains go into the cremator together, parents will not receive individual sets of ashes. Ashes which are collected are likely to be scattered in the crematorium grounds.

For testing:

Any tests or examination of pregnancy remains can affect timescales for burial, cremation or private arrangements. It is helpful if you know that:

- histopathology is likely to require only of a tiny amount of tissue and won't affect timing unless parents want that tissue to be included in the remains for disposal
- fetal karyotyping may delay disposal if all the pregnancy tissue is sent to the lab or if parents want the tissue samples examined to be disposed of with the rest of the remains
- if pregnancy remains are sent for postmortem examination, this will delay burial, cremation or private arrangements
- parents may also want tissue blocks and slides to be reunited with the rest of the remains.

For remembrance:

> **"Some kind of recognition of the pregnancy would help. It's the being left with nothing that's the hard bit."**

While losses that occur before 24 weeks' gestation cannot be registered, there are some options for people in England and Scotland to receive a government-issued certificate; and as at March 2024, it is hoped that Wales and Northern Ireland will follow suit.

Patients who are not eligible for these certificates may wish to purchase one of the Miscarriage Association's designs but it is also worth checking if your hospital/Trust/Health Board offers something similar. Some providers also offer

- a memorial book or garden
- remembrance services or events

Patients might find it helpful to look at our web pages on marking a loss.

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

Think about timing:

…of the conversation itself

It can help to have a basic sentence or two prepared – for example:
"I know this is a difficult time for you, but I need to let you know that we'll be thinking about what to do with the remains of your baby after the surgery. I can tell you what we would normally do and we can discuss it now, or you might prefer to think about it at another time. The information is in a leaflet too."

It is equally helpful to offer information for women who will or may miscarry at home – either because of choosing conservative or medical management or while waiting for active management – for example:

"I know this is a difficult time for you, but I wonder if you want to have some information about what to do with the remains of your baby if/when you miscarry at home. We can discuss it now, or you might prefer to think about it at another time. The information is in a leaflet too."

In either case – miscarriage in hospital or at home – their reaction will give you an idea of whether this is the right time to talk more or not. ***It does, of course, assume that there is written information available – and there should be:***

- Hospital/Trust/Board-produced information
- Miscarriage Association leaflet (especially page 14)
- information about miscarriages that happen at home

… of the decision

All women should be given time to consider the options and information about the amount of time they have to make their decision.

> **"We had to make a decision within a few minutes. At the time I just ticked that I didn't want to know – I wanted the ordeal to be over. I look back now and feel I let my child down"**

Think about the language you use

Most (but not all) women think of their pregnancy as a baby. Most (but not all) prefer you to refer to it that way. Be sensitive to the words the patient (and perhaps her partner) uses: baby, pregnancy, fetus etc., and then use that same language.

Don't make assumptions, however early the loss

Even if there is no recognisable fetus, many, if not most women (and their partners) may still want the remains of their pregnancy treated and disposed of with dignity and respect. Some women spoke of remains being disposed of as clinical waste in front of them and found that particularly distressing.

> **"Rationally I know it is tissue matter but emotionally it is my baby and that needs respect."**

Be aware that reactions will vary and that all are valid. Some people won't want to know or think about disposal, some might be angry that you are talking about it at all. Others will be shocked but still grateful that you are consulting them.

Some people might want to take the remains home without knowing how or where they will put them and this might worry you. You may want to let them know that they can get information and guidance from the Miscarriage Association.

Whatever your personal views are, keep them in check. Above all, try not to express shock or disapproval.

> **"I felt it was my choice to take the remains. It was not what the surgeon would have done and her face and expression said that clearly."**

Be honest

If you are asked a question and don't know the answer, it's best to say so and offer to find out. This prevents misunderstandings and possible hurt and distress.

If you don't like your hospital's policy and procedures, don't be tempted to make them sound different from the reality.

If your hospital policy includes disposal as clinical waste, or incineration off-site, don't describe these as either sensitive disposal or cremation. They aren't. It is better to be honest, even if it is painful.

Again, it may help to have a sentence or two prepared, for example:

"If the pregnancy is very early, we can't always see the embryo or fetus (your baby). In those cases, we usually dispose of the remains along with other blood and tissue."
If they ask how, say *"Along with other clinical waste, which is disposed of safely, usually by incineration".*

In cases like this it might help to suggest other ways the parents can mark their loss.

Got more time?

You might find these resources helpful.

- Miscarriage Association leaflet Your feelings after miscarriage.
- The Human Tissue Authority guidance on disposal of pregnancy remains.
- The RCN guidance on disposal of pregnancy remains.

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 get in touch.

Consider your needs too

Talking to patients about what happens to the remains of their pregnancy can be difficult and distressing – for them, of course, but also for you. You are likely talking with someone who is already in distress about something that may increase those feelings and that can be upsetting for you too. The following suggestions might help.

Identify the difficulties

These may include:

The context:
- if this is your first encounter with this patient
- where the conversation takes place
- time pressure: the need to give the information, including any key time-frames

Particular situations that are difficult or distressing:

- where the patient (and perhaps her partner too) is still reeling from confirmation of her loss and management decisions
- if she doesn't want to talk about this at all
- 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
    - on certain disposal options, including taking the remains home
- fatigue – physical and emotional

Identify your sources of support …

Your most likely source of support will be your peers:

- in your hospital/Trust/Health Board:
- individually, informally
- in staff meetings, training sessions and/or clinical supervision
- peers from other hospitals or clinics:
- individually and informally
- through existing or developing networks like the Association of Early Pregnancy Units and in Scotland, the Scottish Early Pregnancy Network.

You might also consider:

- your partner, if you have one, or a trusted friend
- joining one of the monthly 'Professional Pause' sessions hosted by the Miscarriage Association and the Ectopic Pregnancy Trust[1]
- talking to us 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.

[1] 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.

And finally

Talking to patients about the disposal of pregnancy remains can be a difficult and daunting task. You may feel tempted to get the boxes ticked and run. But you're working in this field because you care about your patients and you want to help them through even the most difficult of situations. You may not get it right for everyone, but patients will always remember your care, kindness and compassion.

> **"The doctor who dealt with this was excellent, her language, her knowledge and consideration of the circumstances was spot on. She stuck to medical [aspects] but she used terms such as baby… she validated the severity of the situation and the loss, and the complicated emotions that are attached to it."**

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