

# Managing the Disposal of Pregnancy Remains

RCN guidance for nursing and midwifery practice





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#### Publication

This is an RCN practice guidance. Practice guidance are evidence-based consensus documents, used to guide decisions about appropriate care of an individual, family or population in a specific context.

#### **Description**

This publication is intended to provide clear guidance for all health care professionals to have in place sound systems and processes to ensure the safe and appropriate disposal of pregnancy remains, where the pregnancy has ended before the 24th week of gestation. This will include following an ectopic pregnancy, early intrauterine fetal death, miscarriage, or a medically or surgically induced termination of pregnancy.

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## 1. Introduction

The aim of this publication is to enable nurses and midwives to have in place appropriate systems and processes to ensure the safe and appropriate disposal of pregnancy remains, where the pregnancy has ended before the 24th week of gestation. This will include following an ectopic pregnancy, early intrauterine fetal death, miscarriage, or a medically or surgically induced termination of pregnancy.

This guidance does not refer to the disposal of embryos created in vitro (for fertility treatment or embryo research), a process which is regulated by the Human Fertilisation and Embryology Authority (HFEA). Neither does it apply to care following stillbirths (when a baby is born dead after 24 weeks' gestation) or neonatal deaths.

This guidance focuses on enabling the woman whose pregnancy it was to choose the method of disposal she feels is most appropriate, and reminds all nurses and midwives of the need to be sensitive and respond to a woman's wishes relating to disposal, regardless of the particular circumstances of the pregnancy loss.

This guidance was revised following the March 2015 publication of the Human Tissue Authority's Guidance on the disposal of pregnancy remains following pregnancy loss or termination for England, Wales and Northern Ireland, and also took account of separate guidance published by the Scottish Government in 2012 (which was also updated in 2015 – see page 6).

The primary message contained here is that all those involved must consider the personal wishes expressed by the woman in relation to the disposal of pregnancy remains. It also recommends that available disposal options, as outlined in the Human Tissue Authority guidance (HTA, 2015), should be articulated in writing or verbally. This recommendation needs to take account of local languages and cultural and/or religious expectations.

This edition also takes into consideration guidance available from **Sands**, the stillbirth and neonatal death charity, the Institute of Cemetery and Crematorium Management (ICCM), and the **Miscarriage Association**, all of which provide operational details for those working in this area of practice.

Appendix 1 provides an overview of the disposal process. It should be noted, however, that differences in interpretation means that all those involved in caring for women should have a detailed understanding of the local operational processes that apply.

Finally, it is recognised that many women will have a partner who may be involved in the disposal decision. While, for ease of reading, this text largely refers to the woman, it should be taken to include a partner wherever appropriate.

## 2. A woman's choice

Because of the very sensitive nature of pregnancy loss, it can be challenging to understand how an individual woman may feel about discussing the disposal of her pregnancy remains.

The critical issue in supporting best practice is in respecting a woman's choice, based on the understanding that this is her pregnancy loss – regardless of the circumstances of that loss – and that she is best placed to determine how the remains should be managed.

When a pregnancy ends, the woman may have very mixed emotions about this, regardless of gestation. It is incumbent on nurses and/or midwives caring for the woman to establish her wishes while recognising that, at what may be an emotional time, it may prove challenging for the woman to make clear decisions.

In the case of termination of pregnancy, the mode of disposal may have a bearing on the way the remains are collected. For this reason it is important for the registered nurse to ensure that the woman knows, before the procedure, what her options are with regard to disposal of the pregnancy remains, and that her choice will be supported and respected.

It is also important to consider how the registered nurse or midwife will support younger women (those under 18 years) to ensure that their views are known and acted upon rather than those of parents, guardians or other relatives who may be supporting them at this time.

Professional judgement, compassion and knowledge are all critical when it comes to providing a woman with the appropriate time and opportunity to discuss her options, and ensure that she can make a decision that is right for her.

Equally, the wishes of those women who do not want any information or discussion, or to be otherwise engaged in decision making about disposal of the pregnancy remains, must also be respected.

# Jisposal of Pregnancy RemainsHTA guidance for England,Wales and Northern Ireland

The Human Tissue Authority (HTA) produced key guidance and recommendations in 2015, based on the Human Tissue Act 2004 which, as the HTA explains:

"... makes no distinction between the disposal of pregnancy remains and the disposal of other tissue from a living person; pregnancy remains are regarded as the tissue of the woman. Although under the HTA consent is not required for the disposal of pregnancy remains, the particularly sensitive nature of this tissue means that the wishes of the woman, and her understanding of the disposal options open to her, are of paramount importance and should be respected and acted upon."

HTA, 2015:2

The HTA guidance makes provision for three options – burial, cremation or incineration. It also acknowledges that women may choose to make their own arrangements, or to have no involvement with regard to disposal at all. The emphasis within the HTA guidance is on the woman's choice.

## Disposal of fetal remains – Scotland

In 2015 the Scottish Government published its guidance on the disposal of pregnancy losses up to and including 23 weeks and 6 days gestation (Scottish Government). In 2015, the Scottish Government published its revised guidance on the *Disposal of Pregnancy Loss Up To And Including 23 Weeks and 6 Days Gestation* (Scottish Government, 2015). The guidance has some key differences from the HTA guidance which applies to England, Wales and Northern Ireland including:

 in Scotland, the minimum options for disposal are collective ('shared') cremation, or where that is not available, collective ('shared') burial, acknowledging also the right of the woman to make her own arrangements for disposal

- the woman's authorisation, in writing, should be obtained, from a written list of all available disposal options
- the pregnancy remains should be retained for a minimum of seven calendar days following authorisation for shared cremation by the woman, to allow for any change of mind
- after the minimum retention period, the disposal of the remains should take place within six weeks of the pregnancy ending.

For more information go to: www.sehd.scot. nhs.uk/cmo/CMO(2015)07.pdf

## 5. Options

Nurses or midwives who provide care to a woman who has miscarried or had a termination of pregnancy have a duty of care to be sensitive to the woman's particular wishes and her understanding of what the pregnancy means to her.

For some women, regardless of the circumstances of the pregnancy loss, this could be a devastating life event, while for others there may be minimal or no attachment to the pregnancy; some women may experience a range of emotions between these two stances.

All health care personnel involved should also fully understand local policy and procedures and know who the key contacts are.

The HTA recommends three options for the disposal of pregnancy remains; cremation, burial or sensitive incineration separate from clinical waste:

"Cremation and burial should always be available options for the disposal of pregnancy remains, regardless of whether or not there is discernible fetal tissue. Sensitive incineration, separate from clinical waste, may be used where the woman makes this choice or does not want to be involved in the decision and the establishment considers this the most appropriate method of disposal."

#### HTA, 2015:5

The HTA also recommends that disposal of the pregnancy remains takes place as soon as is practicable after the woman has communicated her decision. It is important, however, that women who need more time to make a decision are given this opportunity, and that service providers communicate clearly to the woman the timeframes in which a decision has to be made, after which the provider will dispose of the pregnancy remains by a specified method.

Hospitals and other facilities will normally be responsible for the costs of routine modes of disposal, but if a woman wishes to make her own specific arrangements then she may be responsible for any costs associated. For this reason it is important that women are provided with clear information about any potential costs, so that they can make an informed decision about disposal.

The HTA has produced a useful *Frequently asked questions* data sheet for health practitioners, available for download at www.hta.gov.uk, which provides further responses to key issues raised.

#### 5.1 Burial

Pregnancy remains may be buried. It is important to establish local links to ensure arrangements are clearly understood, especially as burial may be in a communal grave. The remains should be in an individual sealed coffin or container, but may then be collected together with other individually sealed remains into a larger sealed container. There may or may not be an opportunity for separate markers to identify the grave, and clearly if the woman/family wishes to be involved, they should be made aware of the details of options available to them.

Whatever the woman's choice, details should be clearly recorded using either the woman's name or a unique identifiable reference number (if confidentiality is an issue), so that, if necessary, her notes can be made available to her at a later date

#### 5.2 Cremation

The cremation of pregnancy remains of less than 24 weeks gestation is not included in *Cremation, England and Wales: The Cremation (England and Wales) (Amendment) Regulations 2017*; however, most crematoria are willing to provide this service. If this service is not currently available locally, arrangements should be explored with crematoria to make provision available.

Details of model agreements can be found in the ICCM's policy and guidance entitled *The Sensitive Disposal of Fetal Remains* (ICCM, 2015), which contains a draft agreement that may be helpful to establishments.

Again, the woman needs to be made aware that pregnancy remains will be in an individual container and may be cremated with other remains (communal cremation) rather than in a separate service. It is important to note that the woman may wish to privately arrange an individual cremation, although there may be a cost for this. Since 2015, a private fetal cremation

service has been available which advertises a tiny cremator with a patented process that retains ashes from even very early gestations. The fee charged includes collecting pregnancy remains from parents and returning the ashes in the chosen container. Further information is available from www.specialcarecremations. co.uk

When discussing the option of cremation, women should also be made aware that there is a risk that ashes may not be recovered, depending on the gestation of the pregnancy loss. Any ashes that are recovered from communal cremations are usually scattered or buried. Sands has produced a helpful position statement containing best practice recommendations in relation to providing parents' choice and accurate information about their baby's ashes, which is available for download at www.uk-sands.org.

### 5.3 Incineration

The incineration of pregnancy remains should also be an option available to women in England, Wales and Northern Ireland, and may be the preferred choice for some women; for example, where a woman does not wish the remains to be afforded any special status; expressly prefers this option; or does not wish to be involved in the decision, preferring to leave it to the care provider to make the necessary arrangements. It should be acknowledged that this option can be viewed as challenging for some people; however, the woman's choice must always be the priority in this decision-making.

Incineration may be the routine method of disposal utilised in situations where the woman does not express any decision about disposal within the maximum 12 weeks recommended by the HTA guidance (see Section 5.4 below). It is also noteworthy that some providers may dispose of fetal remains separately from placental remains, using incineration as the mode of disposal for the latter.

In order for a woman to make an informed decision, it is important that she understands that although incineration and cremation both involve the pregnancy remains being burned, these procedures are not the same and take place in very different environments. Health care professionals involved in supporting the woman

to make her decision should be able to articulate, with accuracy and confidence, the processes employed locally, and ensure that they are able to properly explain this information.

In the case of disposal by incineration, the HTA (2015) identified the need for pregnancy remains to be subject to a different disposal process from general clinical waste. The HTA recommends that prior to disposal the remains should be packaged and stored separately from other clinical waste, in suitable containers, before subsequently being incinerated separately from other clinical waste. For future reference, it is important that the date of the collection and the location of the incineration should be recorded.

In Scotland, incineration is not an option (Scottish Government, 2015).

The need for sensitivity when explaining these processes cannot be over-emphasised and the woman's wishes should always be paramount.

## 5.4 The woman does not make a decision

The premise of high quality care in respect of the disposal of pregnancy remains is centred on enabling the woman to make the right decision for her on the basis of her perception of the meaning of the pregnancy, or what feels most manageable for her at that time. The choice of method of disposal will not necessarily always directly correlate with the woman's attachment to the pregnancy.

If a woman prefers not to make a decision about disposal, she should be informed what method of disposal will be used. Where a woman does not want to engage in any discussion about disposal, her position should be respected but she should be made aware that information is available to access should she so wish.

The HTA (2015) recommends that if a woman does not make a decision, the remains should be kept for no more than 12 weeks before disposal. The woman should be made aware of the local timeframe and that if no decision has been expressed within that time, the remains will be disposed of. Ideally, this information should be provided verbally and in writing.

Sometimes women/parents do not recognise their loss at the time, but may return months or years later to enquire about disposal arrangements. It is therefore important that any discussions and information provided are well-documented, along with the details of the disposal.

## 5.5 Returning the pregnancy remains to the woman

Some women may choose to have the remains returned to them, so that they can make their own arrangements. It will be important to have confidence that the woman has made an informed decision, with careful and sensitive communication, and to ensure that the woman is aware of the options available to her.

If the woman requests that the remains be returned to her, these should be stored in an appropriate container (opaque, watertight and biodegradable) in a safe place and made available for collection by her or her representative.

The decision, and the date of collection, should be recorded in the woman's notes and she should be given written confirmation that she is entitled to take the remains to make her own arrangements.

## 6. Roles and responsibilities of nurses and midwives

Nurses and midwives caring for women who have experienced a pregnancy loss or undergone termination of a pregnancy before 24 weeks gestation should focus on ensuring that women are able to make decisions and choices based on personal needs, and that the woman understands the responsibilities linked with her decisions.

The emphasis for the health care professional should be on providing quality information; it can be a challenge identifying how much information is appropriate, and it is often best to give key choices, and be available to repeat or expand on details as required. There may be variation across the UK about options available, however the HTA guidance for England, Wales and Northern Ireland (HTA, 2015) is clear in recommending that all three choices should be communicated (whether written or verbal), even if not available locally. This too will be important for the woman's choice.

This may require further training and education, in particular to understand local processes and how all options can be made available to all women.

## 6.1 Record keeping

Information provided to women about the disposal of the pregnancy remains, together with details of decisions made by the woman (including the option not to engage in decision-making), should be recorded in her medical notes. For some women, grief related to a pregnancy loss may become an issue many months or years after the event, and so complete records will be important in enabling the woman to manage her bereavement process.

As pregnancy remains below 24 weeks gestation are considered pre-viable, these are not subject to paperwork such as certificates of death, however crematoria and burial grounds are legally obliged to ensure the pregnancy ended legally, so will require a pre-viability form or authorisation to confirm this. In some situations, this form may contain details of several pregnancy losses, as it is not always practical to have separate forms for each individual loss. This is why it is important

that any relevant details are recorded in the woman's medical notes.

#### 6.2 Consent

Consent is important and should be regarded as a critical step in the package of care to ensure a woman has been given the opportunity to make a fully-informed decision.

The documentation may vary, however it should be clearly recorded in the woman's medical notes that she has been given appropriate information about the options for disposal and what, if any, decision she has made. It should also be recorded if a woman declines the offer of information and chooses not to make a decision.

It is not necessary to have the woman sign a consent form in relation to the disposal of the pregnancy remains, although some organisations may opt to do this. Furthermore, it is important to take account of younger women's (aged under 18 years) right to consent, and that this may sometimes be in conflict with parents, guardians or those supporting them.

## 6.3 Multiple pregnancy

The loss of a pregnancy can be very distressing; this may be more complex where a multiple pregnancy is involved, especially where one fetus/baby survives. The Multiple Births Foundation (www.multiplebirths.org.uk) provides support and advice to parents and professionals, and registered health professionals should be knowledgeable and confident if supporting women in this situation.

## **6.4 Cultural and religious beliefs**

Health care providers should be sensitive to the values and beliefs of a wide range of cultures and religions, particularly those prominent in local communities, and should also recognise that those who identify with a particular group may or may not have very strongly held beliefs.

No assumptions should be made based on a woman's cultural or religious background. The best way to proceed is to acknowledge the particular culture/religion and then respectfully and sensitively proceed to explore an individual woman's preferences in relation to the options for disposal.

#### 6.5 Memorials

Some women will want to create memories of their baby or pregnancy, and nurses and midwives should be prepared to advise and support women in doing this.

Many units now have memorial books and books of remembrance which are kept in a hospital religious facility, such as a chapel or prayer room, or a quiet room. Information about this should be easily available to allow the woman to decide if she wishes to use this resource.

If ultrasound scan reports or pictures are available, these may form part of a personal memorial package, along with cards from friends and family.

The memorial process may also involve a religious leader, where appropriate, and a service of remembrance; however, this will be very individual and options need to be clearly understood beforehand.

The **Sands** charity (Sands, 2007) and the **Miscarriage Association** both provide further advice for professionals and parents on the choices available.

## 6.6 Engagement with others

A wide range of health care professionals and other associated service providers may be involved in the process of the disposal of pregnancy remains. Local policies and procedures need to take account of the full pathway of care and consider all those who may be involved, recognising that this may be a sensitive subject for some.

It is important that those handling pregnancy remains understand that these are perceived differently from other body tissue, and should be managed in a respectful manner, as identified by the HTA guidance (HTA, 2015).

There should also be opportunities for all trained and qualified staff, including nurses, midwives, medical teams, health visitors, pathology laboratory staff, those engaged in disposal procedures (including the disposal of clinical waste), porters who may be involved in transporting the pregnancy remains, and so forth, to receive education and training that facilitates their understanding of the diversity of emotional and practical needs of women.

Acknowledgement also needs to be made that staff involved in pregnancy remains disposal may need support should they feel affected by the procedures.

### 6.7 Miscarriage at home

Many women miscarry at home and often do not need to seek medical advice or care within a hospital. Some women may attend their general practice surgery or hospital to have a miscarriage confirmed; they may also choose to take the remains home for burial on their own property, or choose another mode of disposal.

It is important for nurses and midwives working in the community, as well as ambulance and other urgent and emergency care staff, to be aware of local policies on management and options for disposal. The ICCM provides further information on funeral practices and disposal options.

In June 2015 the ICCM, Sands and the Miscarriage Association published joint guidance on miscarriages at home; the guidance and associated documentation is available for download from each organisation's respective websites.

## **6.8 Donation of fetal** tissue for research

This is a sensitive area and health care professionals need to be prepared to answer questions, as women may ask about the donation of fetal tissue for research.

Fetal tissue is required for research purposes, and can often help to advance medical science and support better health and wellbeing in the long term. A licence may be required from the HTA to store fetal tissue for use in research. Establishments should contact the HTA for further information on the licensing and consent requirements relating to the use of fetal tissue for research purposes.

With regards to disposal, the HTA guidance (HTA, 2015) states that women should be informed of the available modes of disposal, where known, and the standard type of disposal used by the facility. Women should also be told whether they will be able to change their mind at a later date. Where options are available, the woman's wishes should be recorded so that these can be acted upon when the time comes.

#### **The National Bereavement Care Pathway**

The National Bereavement Care Pathway (NBCP) helps professionals to support families in their bereavement after any pregnancy or baby loss, be that miscarriage (including ectopic and molar pregnancy), termination of pregnancy for fetal anomaly (TOPFA), stillbirth, neonatal death or sudden unexpected death in Infancy (SUDI).

Further information can be found at: www.nbcpathway.org.uk

## 7. Conclusion

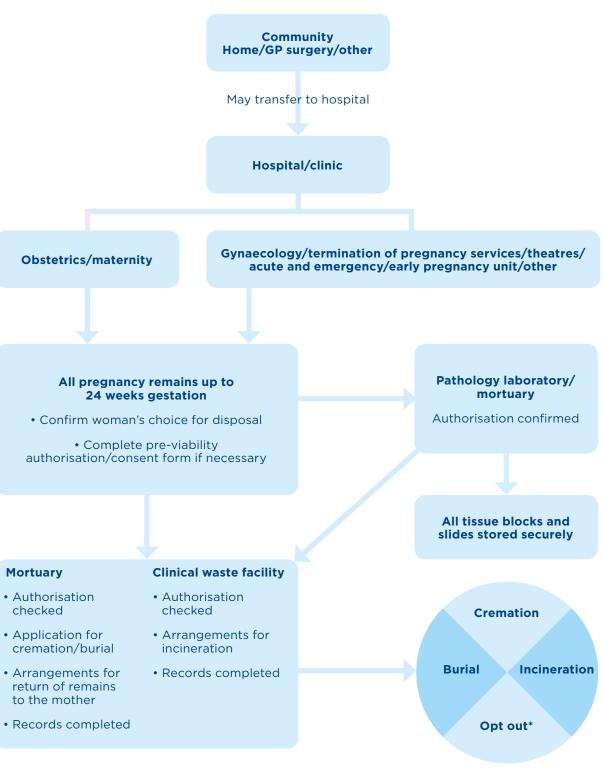
The overwhelming principle here is the need to respect each woman's right to decide on the mode of disposal of the remains of her pregnancy, including not making any decision at all. Clearly, sensitivity will be vital when approaching the question of the disposal of pregnancy remains with women and, where appropriate, discussions with their partners and families.

All service providers that are likely to have contact with women who have experienced a pregnancy loss, regardless of the circumstances of that loss, should be respectful of the need for sensitivity and have clear policies in place that are well-articulated and understood by all those involved; this will apply not just to nurses and midwives, health visitors, health care

assistants, students and medical teams providing front line care, but also those who are involved in laboratories and the transportation of the remains, and personnel working at mortuary and crematoria, burial grounds and clinical waste facilities.

The message for all involved is that the process should be centred on a woman's choice, and that everyone has a professional responsibility to provide effective systems that facilitate that choice with sensitivity and confidence; that the systems will work well; and that inter-agency working is smooth and effective.

# 8. Appendix: Disposal of pregnancy loss - overview



<sup>\*</sup> decision then made by care facility

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