

Guide for consent takers

Seeking consent/authorisation for the
post mortem examination of a baby



“The death of a child is almost the worst thing that can happen to a parent. I say ‘almost’, because surely it makes it even worse not to know why. It is worst of all to have a second child die, knowing that the second death could have been prevented if only the first death had been investigated properly. Good pathology services aren’t there to investigate death; they are there to save life.”

Professor Peter Furness, Past President,
Royal College of Pathologists

“Parents’ needs include impartial, accessible and objective information delivered by empathic and sensitive caregivers, so that they can make choices consistent with their values.”

Heazell et al, 2012

A post mortem examination when a baby has died at any stage during pregnancy, at birth or after birth is always likely to provide useful information.

At the very least, it may exclude some common causes of death. If the parents might consider having another baby, it can help the clinicians try to prevent the same thing happening again. (For research evidence on the value of a post mortem following a stillbirth, a neonatal death, or a termination for fetal abnormality, see Section 8.)

Despite the benefits of perinatal post mortems, rates in the UK are low. Post mortem rates for stillbirths in the UK as a whole fell from 55% in 2000 to 45% in 2009, the main fall being between 2000 and 2002 in the wake of adverse publicity about organ retention. (Rates in Scotland are now increasing again due to a series of practical interventions, see Section 8.5). Post mortem rates for neonatal deaths in the UK fell from 29% in 2000 to 18% in 2009. Again, much of this drop occurred in the first three years of the decade (CMACE 2011). There are no figures available for post mortems after late miscarriages.

About this guide

- ▶ **This guide is part of the Sands *Post mortem consent package*.** It covers the key points to bear in mind when seeking consent or authorisation from parents for a hospital post mortem. It is written both for staff who are not accustomed to seeking consent or authorisation, and also for experienced staff who wish to review their practice in this area.
- ▶ **This is a generic guide** and is not intended to replace information provided locally. It supports any training you have received on seeking post mortem consent.
- ▶ **The guide is intended for health care staff only. It is not written for parents.** Section 6, in particular, contains detailed clinical information about the post mortem process, to enable you to answer specific questions that some parents may ask. However, most bereaved parents will not want to know this level of detail and their wishes should be respected.
- ▶ **The other documents in the Sands *Post mortem consent package* are:**
 - ▶ The Sands *Post mortem consent form* (and a supplementary form *Consent to further examination of organs for diagnostic purposes*). These forms can be downloaded from the HTA website www.hta.gov.uk/policies/post-mortem-model-consent-forms. There is also a downloadable guide, *Adopting the Sands Post mortem consent form in your hospital, trust or health board: Information for decision makers*.
 - ▶ *Deciding about a post mortem examination*, a booklet for parents whose baby has died. You can download a copy from the Sands website www.sands.org.uk/support. You can order printed copies from the Sands shop www.sands.org.uk/shop

All the documents in the Sands *Post mortem consent package* have been developed in consultation with and approved by the HTA.

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¹The legal term under the Human Tissue Act 2004 in England, Wales and Northern Ireland is consent; the legal term in Scotland under the Human Tissue (Scotland) Act 2006 is authorisation.

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1. Key principles

- ▶ All parents should have the option of discussing whether to have a post mortem examination of their baby. The possible benefits should be explained to them so that they can make an informed choice.
- ▶ No assumptions should be made about who will and will not consent to a post mortem on the basis of, for example, religion or ethnicity.
- ▶ All parents should be given the information they need to make their own decisions.
- ▶ Obtaining parents' consent/authorisation for a post mortem should be a process, not just obtaining a signature on a form. The responsibility for giving information and answering questions lies with the consent taker. A form is only a record of what the parents have decided.
- ▶ Parents should never be given a consent/authorisation form without some preliminary discussion. They should never be left to complete it on their own unless they specifically request this.

2. Prerequisites for consent takers

2.1 Consent taker training and sources of information

- ▶ You should have been trained and specifically approved and signed off under hospital/trust/board policies to take post mortem consent/authorisation, or should be deemed to be competent, and should understand the potential benefits to the parents of a post mortem (see Section 8).
- ▶ You should have observed a post mortem examination (HTA Code B:19), if possible that of a baby.
- ▶ You should have read the consent/authorisation policy of your hospital, trust or health board and other relevant local policies and guidelines.
- ▶ You should be completely familiar with the consent/authorisation form that you will be using.
- ▶ You should have read the Sands booklet *Deciding about a post mortem examination: Information for parents*.
- ▶ You should also have read any written information about post mortems for parents produced by your hospital, trust or health board.
- ▶ You should have read the relevant parts of the Human Tissue Authority's Codes of Practice A and B (available at www.hta.gov.uk/hta-codes-practice-and-standards-0).

The Human Tissue Authority (HTA) is responsible in England, Wales and Northern Ireland for ensuring that the requirements of the Human Tissue Act 2004 are met. The HTA produces Codes of Practice that give practical guidance on consent, post mortem examinations, and the disposal of tissue and organs. The HTA's remit does not cover post mortems in Scotland but the standards in its Codes of Practice are widely accepted.

The HTA also licenses and inspects all departments in England, Wales and Northern Ireland that carry out post mortems and that store tissue for future use. It regulates consent

for genetic testing in all four UK countries.

The HTA has approved the Sands *Post mortem consent form* and the supplementary form, this guide, and the information booklet for parents. The Sands *Post mortem consent form* can only be used in England at present. This guide and the booklet for parents are relevant in all four countries of the UK.

Scotland is covered by the Human Tissue (Scotland) Act 2006. Separate consideration is being given in Scotland to a similar form which complies with the Human Tissue (Scotland) Act 2006.

2.2 Knowing about local policies, arrangements and options

When discussing a post mortem with parents, you are in an unusual position: in almost all other situations, the professional who takes consent/authorisation will carry out the procedure. Since this is not the case with a post mortem, it is important to be well prepared so that you can answer parents' questions and record their wishes accurately, and also give clear, unambiguous instructions to the pathologist.

Policies, practices, arrangements and options differ a good deal across the UK. You need to know what happens in your hospital and, if the baby will be sent to another hospital for the post mortem, what happens there. It is also very important that everyone who discusses post mortems with the parents gives consistent, accurate information about local arrangements, what is possible and what may not be possible.

Below is a list of the questions that you need to be able to answer before you talk to the parents.

Practical help for consent takers

All the questions in this section and in Section 7.4 are also listed in the Sands document *Compiling local information for post mortem consent takers* which can be downloaded from the HTA website www.hta.gov.uk/policies/post-mortem-model-consent-forms. Sands recommends that a copy of this document, with the answers filled in, is kept in a *Perinatal post mortem file* in each ward or unit where consent/authorisation

for perinatal post mortems may be sought. This should reduce the burden of work on individual consent takers and ensure that parents get consistent, accurate information. All consent takers should have read the contents of the file so that they are fully informed before they approach the parents.

If there is no such file on your ward or unit, you will need to find out the answers to these questions yourself, either from colleagues or from the relevant pathology department.

If possible, you should also visit the pathology department to which babies are sent so that you can see the facilities and talk to the pathologist or the mortuary manager about how the babies are cared for and what parents might want to know. If this is not possible, you could phone the pathologist or the mortuary manager to discuss these things.

- ▶ Where are the information booklets/sheets for parents about post mortems kept?
- ▶ Where are perinatal post mortems done?
- ▶ Name and contact details of the mortuary and of key members of staff:
 - ▶ Pathologist(s)
 - ▶ Mortuary manager
 - ▶ Bereavement midwife/wives or nurse(s)
 - ▶ Chaplain(s)
 - ▶ Other relevant contacts
- ▶ How long do parents usually have to wait until their baby's body is released?
- ▶ If perinatal post mortems are done in another hospital:
 - ▶ When would the baby be taken?
 - ▶ When would the baby be returned?

- ▶ How would the baby be transported?
- ▶ How is the transport arranged and who arranges it?
- ▶ How do you contact them?
- ▶ If an urgent post mortem (the baby's body released within 24 or 48 hours) is a religious or cultural requirement for parents:
 - ▶ What are the arrangements for this?
 - ▶ Whom should the funeral director contact to collect the body out of hours?
- ▶ If parents don't want tissue blocks and slides to be kept as part of the medical record:
 - ▶ What are the arrangements for hospital disposal?
 - ▶ How long are blocks and slides usually kept before disposal?
 - ▶ If parents want the blocks and slides returned to them, when and how will this be arranged?
- ▶ If parents have any remaining concerns about the post mortem:
 - ▶ Can they talk to the pathologist (or to an anatomical pathology technologist) about the post mortem, either face-to-face or on the phone?
 - ▶ How can this be arranged?
- ▶ If parents change their minds about what they have agreed to:
 - ▶ What is the time frame for changing their minds?
 - ▶ Whom should they contact, in and out of hours?
- ▶ If parents initially refuse a post mortem but later change their minds, whom should they contact?
- ▶ When is the appointment to discuss the final report likely to be?
 - ▶ How will the parents be informed?
 - ▶ Whom will they see?
 - ▶ Where will the meeting take place?
 - ▶ Can you reassure them that they will wait in a separate area from other parents and babies?
 - ▶ Will they be given a summary of the findings or the complete report?
- ▶ If parents want to see their baby after the post mortem:
 - ▶ Where would this take place?
 - ▶ How do they arrange it?

Funerals (see Section 6.6). If parents ask about funeral arrangements, you will need the following information:

- ▶ Does the hospital offer to arrange and pay for funerals following:
 - ▶ A late miscarriage?
 - ▶ A stillbirth?
 - ▶ A neonatal death?
- ▶ If burial is an option, are shared graves used?
- ▶ Who is responsible for organising hospital funerals? (Name and contact details)
- ▶ What are the arrangements for sensitive disposal of the remains of babies who were miscarried early?

If one or more organs might be kept after the baby's body is released from the mortuary, you also need to know the answers to the questions in Section 7.4.

3. Preparing for your discussion with the parents

A recent UK-wide study found that health professionals and bereaved parents often have very different views on why parents whose babies were stillborn may refuse consent/authorisation (Heazell et al 2012):

- ▶ A significant number of professionals felt that the important barriers to parental consent were: lack of rapport with the professional, the parents' emotional distress, staff workload, negative media coverage about post mortems, and religious or cultural issues. Some professionals also felt that long and unnecessarily detailed forms were a deterrent because they added to parents' distress.
- ▶ Just under half of all the parents who responded felt that emotional distress was a strong barrier to consenting. However, for most parents, the only other things that they thought might be slightly likely to stop people consenting were distressing practical problems such as the length of time it would take to get the post mortem results, and the need to transfer the baby to a different hospital for post mortem. (Religious and cultural issues were not reported as significant by the parents in this study, but the majority of respondents were of white British origin.)
- ▶ Most parents consented to a post mortem because they wanted to find a reason for their baby's death. About half also wanted to contribute to research into stillbirths and to try to prevent the same tragedy happening to other parents.
- ▶ Although most parents were satisfied with the decision they had taken, those who had refused a post mortem were significantly more likely to be dissatisfied than those who had consented to a post mortem.

- ▶ Whenever possible, the parents should have been given clear written information about post mortems and have had time to read it before the discussion. The booklet *Deciding about a hospital post mortem examination: Information for parents* is available from Sands (see page 3 for contact details).

However, even if bereaved parents have already been given written information about a post mortem, you cannot assume that they have read and absorbed it.

- ▶ Grief and shock affect people's ability to understand and speak a second language. If either or both parents have English as their second language, try to organise an interpreter, if possible someone who has already interpreted for these parents (see also Section 5.3). If no interpreter is available, organise an appointment with a telephone interpreting service.
- ▶ If you have not been caring for the parents up to now, read the hospital notes so that you are familiar with the medical history. This will help you to avoid inadvertently making insensitive comments, or asking for information that has already been documented. For example:
 - ▶ Whether the baby died before, during or after birth.
 - ▶ Whether the baby has a name. If so, you need to know it and use it. If no name has been given, take your cue from the parents. For instance, if they use the word "baby", then you should too.
 - ▶ Whether the pregnancy was terminated because of a fetal abnormality and, if so, whether feticide was performed. In these cases, special sensitivity is required as parents have had to make very difficult and painful choices which can only add to their grief.

- ▶ Whether the baby is one of twins or more babies, and whether the other baby or babies have also died.
- ▶ You may also need to find out whether there are any special considerations. For example:
 - ▶ How useful would a limited or external only post mortem be in this case?
 - ▶ Are there any additional tests or examinations that should be discussed with the parents, for example, detailed examination of one or more organs? Would this affect the timing of the release of the baby's body?
 - ▶ Should the parents be advised to say goodbye to their baby for the last time before the post mortem (for example, if the baby died some time before birth, was very small or oedematous, or if the funeral is to be delayed for a long time in order to return an organ to the body)?

4. The discussion

4.1 When to discuss a post mortem

There are no rules about a good time to raise the subject of a post mortem with parents whose baby has just died. Of necessity, parents usually need to be asked about having a post mortem fairly soon after their baby's birth and before they go home.

It may sometimes be helpful to prepare parents by mentioning the possibility of a post mortem some time before you discuss formal consent/authorisation. However, unless the parents raise the subject themselves, it is not appropriate to discuss post mortem consent/authorisation in detail immediately before induction for an intrauterine fetal death (IUFD), or when a woman is in labour or has just given birth.

If parents are considering a termination for fetal abnormality (TOPFA), it may be appropriate to discuss a post mortem with them at an antenatal counselling appointment. The possibility of a post mortem should also be discussed if it will affect the choice of method: a complete post mortem cannot be done after a surgical termination. If the parents want a post mortem, the consent/authorisation form may be completed before the termination, provided they agree to this.

In a neonatal unit it may be appropriate to mention to parents the possibility of a post mortem when it is clear that the baby is likely to die, or when decisions about palliative care are discussed. However, consent/authorisation should not usually be sought until a suitable time after the death.

4.2 Giving information to grieving parents

"Healthcare professionals and other suitably experienced people involved in seeking consent need to tailor the information they provide to each specific situation... Some people may require in-depth detail, whereas others may prefer to give consent having only had the basics of the procedure explained to them." (HTA Code A, 2017: 21)

- ▶ Individuals want different amounts of information about what happens during a post mortem. You need to strike a balance between making sure that parents understand what they are agreeing to, and distressing them with detail that they do not need. The Sands *Post mortem consent form* and information booklet for parents contain a level of detail that is likely to be acceptable to most parents.

- ▶ It is generally best to begin broadly and then give more detail depending on the parents' responses. For example, if the parents are prepared to consider a post mortem, begin by finding out what type of examination they want: complete, limited or external only. This discussion should give you a clearer sense of the parents' feelings about a post mortem and the level of information they are likely to want.
- ▶ It is very important to give honest answers. If parents ask questions you can't answer, say that you don't know but you will find out and tell them as soon as possible.
- ▶ It is a good idea to have an empty tissue cassette and a glass slide with you when you see the parents in case they want to know about blocks and slides in more detail. The pathologist or the mortuary manager can send you samples.

4.3 The discussion itself

- ▶ Find a time when both parents (and/or someone else if the mother requests this) can be present for the discussion.
- ▶ Find a quiet place to talk where you will not be disturbed. Turn off phones, pagers and beeps. Introduce yourself if necessary; express your sympathy at the death of their baby.
- ▶ Explain why you are there. Acknowledge that this is an extremely difficult subject for the parents to have to think about, and explain why it needs to be done so soon after their baby's death. (In the case of a TOPFA, if a post mortem needs to be discussed before the termination, explain why.)
- ▶ Create an atmosphere of trust, and don't appear to be under pressure or in a hurry. Make sure that parents have enough time to ask all the questions they want.
- ▶ Parents are likely to find it very difficult to listen and to concentrate. Speak slowly and calmly. Listen carefully. Allow time for them to take in what is being discussed.
- ▶ In general, talk about "your baby" not "the baby" and use the baby's name if one has been given. Use "him" or "her", never "it". A few parents may use the word "fetus". Take your cue from them.
- ▶ Remember that parents always feel responsible for their baby, even after his or her death. They need to know that their baby will be kept safe and will always be treated with care and respect.
- ▶ Use clear, simple language and be very careful in your choice of words. Use words that are gentle and not too graphic, and keep descriptions brief unless the parents ask for more detail.
- ▶ Explain the potential benefits of a post mortem (see Section 8), the different options, and the amount of information that each is likely to provide (see Sections 6.1 and 6.2). It is also important to make it clear that sometimes a post mortem does not find a definite cause of death. However, it may still answer many important questions and rule out some possible causes.
- ▶ If the parents clearly do not want to discuss a post mortem, or say during the discussion that they don't want a post mortem, accept this and say that, unless they object, you will check back with them a little later, to make sure that they haven't changed their minds.

If you receive a second refusal, ensure that they know whom to tell if they do change their minds in the next day or two. Record your offer(s) of a post mortem and the parents' refusal in the mother's and/or the baby's medical notes. It is important that parents do not feel harassed by being asked more than twice or by several different people.

- ▶ Before you begin to complete the form, explain that, even after the parents have signed, they can change their minds about anything they have agreed to. Many parents find this helpful as it reduces their anxiety about making irrevocable decisions and enables them to focus. However, if parents want an urgent post mortem, they need to know that there may not be time for them to change their minds. Make absolutely sure the parents know whom to contact if they do change their minds. Make sure that they have the necessary phone numbers (including out-of-hours arrangements), and that they understand the time frame (see Section 5.5).
- ▶ Some parents will not want to make up their minds immediately but will want time to think or to consult other people. Some may want to take religious advice. They should be encouraged to take the time they need but should also be told that ideally a post mortem should be done in the next few days: it will give less information once the baby's body begins to deteriorate. Ask the parents to let you or another member of staff know as soon as they are ready to talk about post mortem consent/authorisation again.
- ▶ During the discussion, make sure, without putting the parents under any pressure, that they understand how the decisions they make about the post mortem may affect the information that can be gained. For example, the implications of decisions about what can and cannot be examined; whether genetic analysis can be carried out; and whether blocks and slides and other material can be kept as part of the medical record for possible re-examination in the future. If you know that certain investigations are particularly important in their baby's case, discuss these.
- ▶ Explain to the parents that there may be observers who, as part of their professional training, need to see a post mortem (HTA Code B, 2017: 24). If the parents do not want any observers, note this on the form.
- ▶ Occasionally, parents may be asked to consent to one or more organs being kept for longer to enable fixation and for more detailed examination or referral to another specialist (see Section 7). This is more likely if the post mortem is being done in a unit that specialises in investigating certain conditions, or in Northern Ireland, where it is customary to hold the funeral within two or three days. If retaining one or more organs is recommended, make sure that the parents know why it is being recommended, the potential benefits, and also, if they want the organs returned to the baby's body before release, that the funeral might have to be delayed. If they find a delay unacceptable, speak to the pathologist to try to find a solution that will produce as much information as possible while still meeting the parents' wishes.
- ▶ Tell the parents when they are likely to get the results of the post mortem, and where and how this will be done. If necessary, explain why it may be some time until the results are available. Many parents who consent to a post mortem feel that their lives are "on hold" until they get the results, and this appointment has huge significance for them. They should be told who will discuss the results with them, roughly how long the appointment will be, and where it will be. Note that the parents should never have to wait for this appointment in a room with other parents and babies.
- ▶ There are many reasons why parents may refuse or have doubts about a post mortem. For

example, they may be unable to bear the thought of anything more being done to their baby and want him or her to be left in peace; they may find going through the consent/authorisation form and the details of a post mortem too daunting; they may not believe that they will gain any valuable information; they may worry that they have in some way contributed to their baby's death and that a post mortem will confirm this; they may be deterred by the prospect of delaying the baby's funeral; they may be influenced by religious or cultural beliefs. It is important to be aware of and accept possible cultural or religious beliefs, but not to assume that individuals of a particular religious or cultural group will therefore not want a post mortem.

- ▶ Every parent has the right to refuse a hospital post mortem and parents should never be pressurised to consent. However, if parents are not sure, it may sometimes be possible to allay their fears or to suggest a way forward that will still provide some information:
 - ▶ Many parents worry about the way their baby will be treated while he or she is away from them. Reassure the parents that their baby will be kept safe and treated with great care at all times. The baby can go to the post mortem dressed in his or her own clothes or blanket and, if the parents want, with a toy or other item. When the baby is released, he or she will be dressed in the same clothes or blanket and with the toy or other item.
 - ▶ If you know the mortuary staff and how things are done, you can give the parents more detailed information about how their baby will be cared for. Note any particular concerns or wishes about the care of the baby on the consent/authorisation form. The parents may also find it helpful to talk to the mortuary manager or one of the mortuary staff themselves to find out how their baby will be looked after. If the parents are worried, for example, about their baby being left in the dark, it may be possible to arrange for a light to be left on in the mortuary.
 - ▶ If parents do not want to delay the funeral, it may be possible to fix the organs for a shorter time. For some parents it is very important to hold the funeral within 24 hours of the death. Some may consent to an urgent post mortem if this can be arranged. If you are not sure if the parents' wishes can be met, offer to check with the pathologist or one of his/her team yourself, or to arrange for the parents to speak to the pathologist.
 - ▶ Sometimes a solution can be reached that will produce some useful information and still be acceptable to the parents, especially if an answer to a very specific question is required. In this case, a targeted biopsy or biopsies taken through a limited, small incision or incisions may be helpful; previous surgical incisions might even be used when possible.
 - ▶ However, it is always essential to check with the pathologist that the suggested examination will answer the parents' questions and, if this is also a requirement, that it can be completed in time. There is no value to anyone in carrying out an examination that will not provide any answers. It is very important that the parents understand how much information the examination they agree to is likely to provide.
 - ▶ If family or community members will wash the body before the funeral, make sure that parents who are considering an invasive post mortem know that the incisions will be visible.
- ▶ The placenta should always be examined if possible. This is particularly important if the parents want only a limited post mortem or do not want a post mortem at all (see also Sections 5.1, 6.3 and 8.2).

5. Consent/Authorisation

5.1 When is consent required?

Consent/Authorisation must always be obtained for the hospital post mortem examination of a baby, whether born alive or dead, and at any gestation. Consent/Authorisation is also required for all genetic testing, including of placental samples, particularly where this involves DNA.

The only time when parental consent/authorisation for a post mortem on a baby is not needed is when a coroner or procurator fiscal orders a post mortem (see Section 5.6 below). In a coroner's or procurator fiscal's case, the parents should still have a full explanation of what is happening, and should always be informed about the results in full.

When parents are not present

Consent/authorisation should normally be obtained in writing. However, if the parents are not present (for example, if they have gone home and further consent/authorisation is sought to retain an organ – see Section 7.1), they can give their consent/authorisation over the phone, by email or by fax. It is always important that they are given adequate information about what they are agreeing to, and can ask questions.

If the parents give verbal consent/authorisation but do not actually sign the form themselves, it is essential to record the discussion in the medical record: explain why the discussion was not face-to-face, note what was discussed and that consent/authorisation was discussed and given, and any special points (HTA Code A, 2017: 14-15). If the parents do not consent, this should also be noted in the records.

Examination of the placenta

Consent/authorisation to examine the placenta should always be sought as a matter of general health care law and good practice (see also 8. 2). It can be verbal rather than written. In this case, a note should be made in the mother's medical record.

5.2 Who can sign a consent/authorisation form?

- ▶ Consent/authorisation should always be obtained from the mother, unless there are exceptional circumstances, eg, if she is too ill to consent.
- ▶ Wherever possible, the father's consent/authorisation should also be sought.
- ▶ If both parents are present, they should both sign the form.

If the parents disagree

In **Northern Ireland**, a father who has never been married to the baby's mother or (in the case of a neonatal death) whose name has not been included on the baby's birth certificate, only has the right to give consent if he has acquired it through a parental responsibility agreement with the mother, or a court order (DHSSPS 2003).

There is as yet no legal guidance in **England and Wales** on what to do in this situation. Current advice is that if the mother wants a post mortem and the father does not, the mother's wishes

should be respected because the results of the post mortem may help her in the management of any further pregnancy. If the father wants a post mortem and the mother does not, it may be worth seeking legal advice from the hospital lawyers as the status of the father will be a matter of fact in each case (for example, he may be married to the mother or have registered the birth).

In **Scotland**, there is guidance from the Scottish Executive: "Where both parents are available, it is always best that they agree on whether or not a post mortem examination can be done. Where only one parent is available at the hospital, he or she will be asked if they think the other parent would object. The post mortem examination can go ahead if only one parent authorises it. However, if the other parent objects or would be likely to object, then usually the post mortem examination would not be done. There may be unusual circumstances in which parents disagree strongly over whether a post mortem examination should be done. Where this disagreement cannot be resolved through discussion, the post mortem examination would not usually go ahead." (Scottish Government 2003)

5.3 What if there are communication difficulties?

Particular consideration should be given to the needs of individuals and families whose first language is not English.

When a father, for example, speaks better English than the mother, staff often use him to interpret. However, even if his English is fluent enough to deal with the specialist language required, he is likely to find it almost impossible to interpret properly while at the same time coping with the distress and shock of his own loss. As a result, the baby's mother may receive only a partial explanation or may be unable to participate fully in any discussion. Couples should always be offered the help of a trained interpreter, even if one parent speaks English (Schott et al 2007).

Record in the notes any difficulties in communicating with the parents, eg, because of language, literacy or hearing difficulties, and an explanation of how these difficulties were overcome, eg, through an independent translator (HTA Code A, 2017: 15).

5.4 Confidentiality

All the usual rules of patient confidentiality apply in relation to post mortems. Some parents may decide to have a post mortem even though other family members or other people regard this as unacceptable. The need for particular care with confidentiality should be noted on the consent/authorisation form.

5.5 What if the parents change their minds?

It is very important that parents know that they can change their minds about anything that they have agreed to, and that they are given a time frame for this. Parents should have a minimum of 12 hours – the HTA recommends 24 hours – between giving consent and the start of the post mortem examination (HTA Code B, 2017: 20). Consent takers should also take individual parents' needs and wishes into account in setting a time frame. There is no set time or system in place in Scotland, but all parents should be given the opportunity to change their minds, and should be given information about whom to contact and by when.

If any part of the post mortem consent/authorisation is changed or withdrawn:

- ▶ The relevant pathology department must be informed immediately face-to-face or by phone.
- ▶ A replacement consent/authorisation form should be sent by fax or email to the pathologist to enable the post mortem to be carried out. If this is not possible, a copy of the existing consent/

authorisation form should be amended, with the changes dated and initialled, and the form faxed or emailed to the pathologist. A copy of the replacement form, or of the amended form, should be placed in the mother's or baby's medical record.

- ▶ Whenever possible, all this should be done by the person who originally obtained consent/authorisation. The name of the person who has changed the form and the evidence (eg, telephone conversation, email, letter) must be recorded on the form and in the medical record.

Consent/authorisation for quality assurance, research and teaching can be withdrawn at any time; there is no time limit. Parents who have consented to quality assurance, research and/or teaching should be advised that if they want to withdraw their consent/authorisation later they should contact the histopathology unit of the hospital.

5.6 A coroner's or procurator fiscal's post mortem

Deaths may be reported to the coroner (procurator fiscal in Scotland) for a number of reasons. In the context of a neonatal death, it is usually because the cause of death is not known or, sometimes, because there is a suspicion of trauma or medical error. Coroners and procurators fiscal do not usually investigate stillbirths unless there is uncertainty as to whether the baby was stillborn (eg, an unexpected home birth). A decision whether or not to report a death to the coroner/procurator fiscal should be taken before asking parents for consent/authorisation for post mortem examination. A coroner's/procurator fiscal's post mortem should not be used as an alternative way of obtaining a post mortem examination after parents refuse consent/authorisation.

Although parental consent/authorisation for the post mortem is not required, the parents will require explanations of the procedures. The post mortem examination will be essentially the same as that for a hospital post mortem examination and is usually carried out by a specialist perinatal pathologist. Tissue samples and other material will be taken but, once the coroner's/procurator fiscal's investigations are completed, the parents will be asked what they would like to happen to this material, including tissue blocks and slides.

The parents may be told the cause of death by the coroner/procurator fiscal. However, they will almost always also need a full explanation of the findings from the consultant in charge or their GP. Clinicians can obtain copies of the post mortem report directly from the coroner/procurator fiscal or, with the latter's permission, from the pathologist.

5.7 Teenage mothers

A teenage mother can give consent/authorisation provided she is able to understand what is involved in the decision, and is able to weigh up the information to make her own decision.

A younger teenage mother may sometimes have an older adult present who may wish to encourage her to decide one way or the other. The final decision must be that of the mother herself. In some circumstances, it may be appropriate to encourage the older adult to give time and space to the mother to make her own decision. Any particular tensions, or where it appears that the mother feels under pressure to agree to what the older adult is proposing, need to be acknowledged and, where appropriate, recorded on the form and in the notes.

If it is clear that the teenage mother is unable to make her own decision, see Section 5.8 on mental competence.

5.8 Mental competence

It is important that the person making the decision about a post mortem has the legal competence to give consent/authorisation. In most cases you can assume that the mother has competence to make the decision unless there is evidence to show that she does not. A history of mental illness should not be taken as evidence that a mother lacks the competence to make a decision about a post mortem. Even where a mother has significant learning difficulties, it is not automatically the case that she is not competent to make a decision about a post mortem.

If you believe that the following elements hold true for the mother, there is a chance that she may lack competence to make a decision about a post mortem. In this case, you need to seek further advice from her treating clinician. The elements are:

- ▶ She is unable to understand the information in relation to the decision about a post mortem.
- ▶ She is unable to retain that information.
- ▶ She is unable to use or weigh that information as part of the process of making a decision.
- ▶ She is unable to communicate her decision in any way.

6. More detailed information about post mortems

These are additional details that consent takers need to know so that they can answer confidently if the parents ask for any more information. This level of detail should only be given to parents if they specifically ask for it. If parents ask detailed questions that you can't answer, say that you don't know but will find out and tell them as soon as possible.

6.1 A complete post mortem examination

A complete post mortem examination consists of an external examination of the baby, an internal examination of the organs and, if the pathologist feels they would be helpful, ancillary tests such as bacteriology, virology or genetics. The initial post mortem examination itself usually takes about three hours. Pathology practices and approaches may vary somewhat in different units.

The initial external examination includes a detailed description of the baby (specifically noting any abnormalities, maceration, assessment of gestational age and intrauterine growth), recording body measurements, taking clinical photographs and a full body x-ray (often called a babygram). The photos and x-rays form part of the post mortem record. The placenta is usually examined if it is available.

The internal examination is made through a longitudinal incision on the front of the body, usually from the top of the sternum to just above the pubic bone, and another incision around the back of the scalp. There may be other lateral incisions on the body.

All the major internal organs are removed, weighed and examined carefully. Small samples of tissue (up to postage-stamp size and a maximum of 5 mm thick) are taken from the organs for examination under the microscope. Tissue may also be taken from other areas, for example, the bones if a skeletal dysplasia is suspected, or the skin if there is a rash. If the organs are extremely tiny, a whole organ may occasionally be examined under the microscope. Organs may also be fixed in formalin to enable examination – see Section 6.4. The pathologist also examines the main

blood vessels, the muscles and the skeleton.

The tissue samples are embedded in paraffin wax in plastic containers (cassettes) to produce permanent "tissue blocks". Each cassette is carefully labelled with the baby's unique identifying number. The tissue blocks (ie, wax plus tissue sample) vary in size, from about the size of a two pence coin to the size of a very small matchbox. Very thin slices (sections) are cut from these blocks (maximum 0.005 mm, ie, less than a tenth of the thickness of a human hair), placed on glass slides and stained with dyes for examination under the microscope.

Once they have been examined and samples taken, the organs are replaced in the body, though not necessarily in the same positions. Then the incisions are carefully repaired by suturing or gluing, just as they would be after an operation. After the post mortem, the marks from the post mortem are not usually visible when the baby is fully dressed.

6.2 A limited post mortem examination

A limited post mortem is carried out in the same way as a complete post mortem, but only certain areas of the body are examined, for example, the chest and neck, the abdomen or the head. Sometimes, parents may not wish a particular part of the body to be touched. In other circumstances, a limited post mortem examination will focus on the part of the body shown to be abnormal by, for instance, ultrasound scan. This may be a specific cavity or an organ such as the heart or the brain.

A disadvantage of a limited post mortem is that it may not pick up other, sometimes relatively minor, abnormalities or appearances that put the main abnormality into the context of a syndrome with a specific recurrence risk.

The incisions will sometimes differ slightly from the standard post mortem incisions, depending on what is to be examined.

For a description of an **external examination** see Section 6.1, paragraph 2.

6.3 Examination of the placenta

Many babies die as a consequence of placental disease, and examination of the placenta very often provides useful information after a late miscarriage, stillbirth or a neonatal death (see Section 8).

The placenta should be examined whenever possible. Examination of the placenta is especially important if the parents do not want a post mortem (see Section 5.1).

6.4 Preparing organs for examination

It is often necessary to fix an organ in formalin so that the pathologist can perform a detailed macroscopic examination and also take tissue samples for further histological examination.

Fixation may take between a few days and two weeks, depending on the size of the organ. Examining the brain without fixation is often impossible. Detailed examination of the brain is particularly important when scanning has identified a brain abnormality, or when important information could be gained about the cause of death. For example, changes in the brain can sometimes explain the process that led to the baby's death, and may provide information about the timing and severity of hypoxia.

In cases of complex congenital heart defects, fixation of the heart can make thorough examination and investigation possible.

Examining organs, fixation and taking samples are nearly always done while the baby is still in the mortuary. The organs are then replaced in the baby's body before the baby is released. The normal time until release varies but is usually 5 to 10 days. If the baby is sent to another hospital for the post mortem, it may sometimes be longer, depending on transport arrangements. (See Section 7 on retaining an organ after the baby's body is released from the mortuary, and what you need to know if you need to seek consent/authorisation for this.)

6.5 Tissue blocks and slides

Under the Human Tissue Act 2004, specific consent is required to keep tissue blocks and slides as part of the medical record for possible future diagnosis. Keeping tissue blocks and slides is very strongly recommended because it may be helpful to the parents in the future: it may be possible to do more tests if more sophisticated techniques become available. It may also be possible to re-examine the tissue samples if further information becomes available or more questions are asked. This may modify the initial interpretation and conclusions.

If parents do not want the blocks and slides to be kept as part of the medical record, they can ask the hospital to dispose of them, or can make their own arrangements for disposal (see below). They need to know that once the blocks and slides are disposed of, it will not be possible to review the diagnosis at a later date. The parents' decision and their wishes about what should be done with the blocks and slides should be recorded in the relevant notes section(s) on the form.

Blocks and slides that are kept as part of a medical record must, like all other items that make up the record, be kept for at least 25 years.

Note: In Scotland, tissue blocks and slides removed during a post mortem may be kept as part of the medical record without specific authorisation (The Human Tissue (Scotland) Act 2006, Sections 38 and 39, Part 3). However, authorisation is required if they are to be used for education, training or research. In all UK countries, specific separate consent is required to take tissue samples for a specific research project.

Disposing of blocks and slides Blocks and slides can either be disposed of by the hospital or released to the parents.

There are strict health and safety rules governing disposal. For health and safety reasons wax blocks cannot usually be incinerated and must be disposed of by a specialist contractor. Glass slides melt and cause problems in crematoriums, so most crematoriums will not accept them.

The parents can choose to have the blocks and slides released for burial. The timing of this and local arrangements vary, but in most places is several months after the baby's death. They will then need to decide what to do with them.

- ▶ They can decide to delay the funeral until the blocks and slides are released and bury them beside the baby in the coffin. They need to know how long this is likely to be. Some hospitals do not release blocks and slides until after the final post mortem report.
- ▶ If the funeral has already taken place, it will not normally be possible to bury blocks and slides with the baby. If the baby has been buried in a shared grave, it will not be possible to re-open the grave to bury them. If the baby is in a single grave, permission must be obtained from the cemetery owner to open the grave.

- ▶ If the parents will be arranging the funeral themselves, they can ask their funeral director if he or she is willing to take the blocks and slides some time after the funeral, usually for separate burial. There are likely to be additional costs which the parents would have to pay.
- ▶ Parents can also have the blocks and slides returned to them. However, parents who choose this option often find that they don't know what to do with them. They should be reassured that they can change their minds at any time, and can then ask the hospital either to store them as part of the mother's or the baby's medical record, or to dispose of them.

6.6 Choices about a funeral

6.6.1 Babies born at or after 24 weeks gestation

By law, all babies born at or after 24 weeks gestation must be formally buried or cremated. Many hospitals offer to arrange and pay for a funeral if this is what the parents want. Depending on local policy this may be burial or cremation. Parents who choose a hospital funeral can usually decide how much they want to be involved. Alternatively the parents can arrange the funeral themselves.

6.6.2 Babies born dead before 24 completed weeks of pregnancy

There is no legal requirement to formally bury or cremate a baby who was born dead before 24 completed weeks of pregnancy. However, many hospitals offer to arrange and pay for a funeral if this is what the parents want. Depending on local policy this may be burial, possibly in a shared grave, or cremation. Parents who choose a hospital funeral can usually decide how much they want to be involved. Alternatively the parents can arrange a funeral themselves.

6.6.3 Fetal remains

The clinical term "fetal remains" is used for a pregnancy loss if there is no recognisable body. This term should not be used in discussion with parents. For most parents it is better to use a phrase such as "the remains of your baby". However, a few parents may not want to think of their loss as a baby and may prefer the term fetus.

The parents may wish to take the remains of their baby themselves. If they do not, the hospital should ensure sensitive disposal in line with *Sensitive disposal of all fetal remains: Guidance for nurses and midwives* (RCN, London 2007). If you are requesting consent/authorisation for a post mortem following an early miscarriage, you will need to know what happens in your unit, since local policies vary.

7. Retaining organs

7.1 When is it necessary to seek specific consent?

The Human Tissue Authority has confirmed that additional specific consent is not required to keep an organ outside the body for examination to establish the cause of death if the organ will be returned to the baby's body before it is repaired and released from the mortuary. This is because it is part of the post mortem examination, for which consent has already been given. Parents only need to be asked specifically for consent to keep an organ if it is recommended that the organ is kept for further examination or a specialist opinion beyond the time when the body will be released.

England, Wales and Northern Ireland

The Human Tissue Authority's statement on when it is necessary to seek consent to retain an organ covers these three countries.

Scotland At the time when this document was finalised, no decision had yet been made about when it is necessary to seek authorisation to retain an organ. This section may, therefore, not be relevant in Scotland. Because of this, we use "consent", rather than "consent/authorisation" in this section.

It is very important, before you talk to the parents, to understand normal local practice, to be familiar with the form that you will use, and to know whether the circumstances may require you to seek consent to retain one or more organs. Discussion with the pathologist may be helpful.

In most hospitals, organs are never or very rarely retained, so the consent form you use may not contain any questions about this.

In Northern Ireland, it is customary to hold the funeral within two or three days and so the current Northern Irish consent form does include questions about retention.

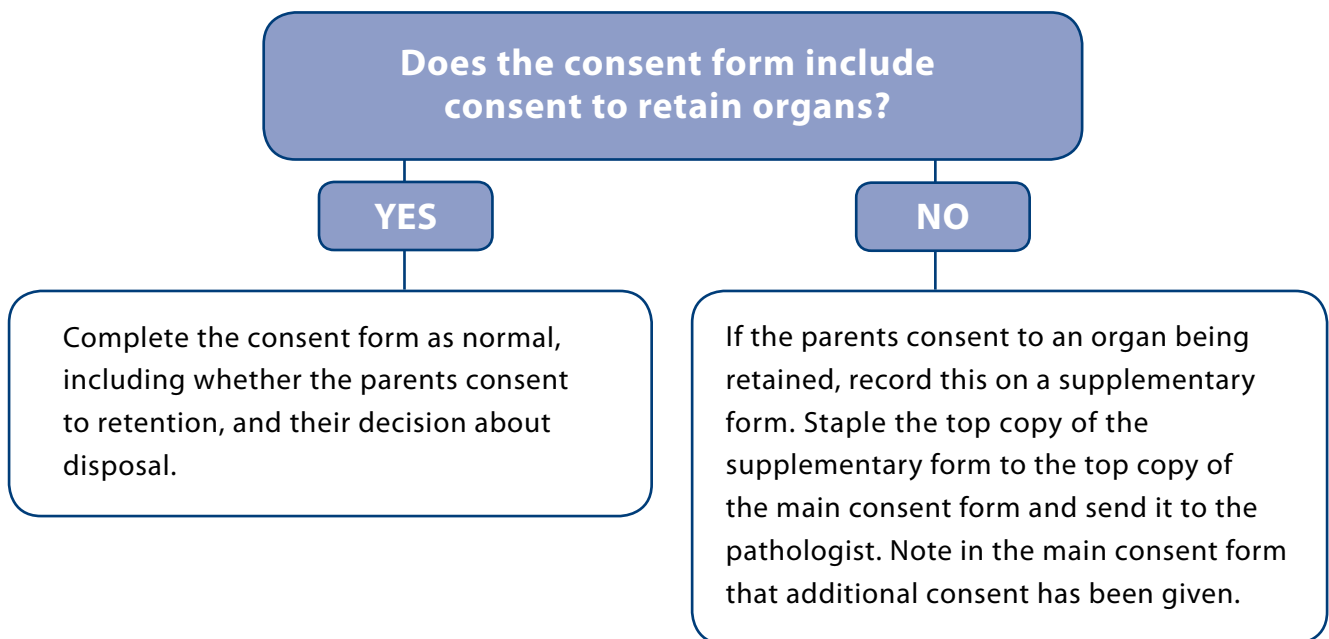
In hospitals elsewhere, especially those with specialist paediatric cardiac or neuropathology units, consent to retain an organ may be helpful. Retention may assist detailed examination and diagnosis or, occasionally, research. The consent form in these hospitals may, therefore, include questions about retention, as well as questions about what should be done with the organs afterwards. You need to know whether parents should always be asked for consent to retain an organ, or only when the organ is likely to be kept beyond the time when the body would normally be released.

Terminology In this document, we only use "retain" to mean keeping one or more organs for further examination or a second opinion beyond the time when the baby's body would normally be ready for release from

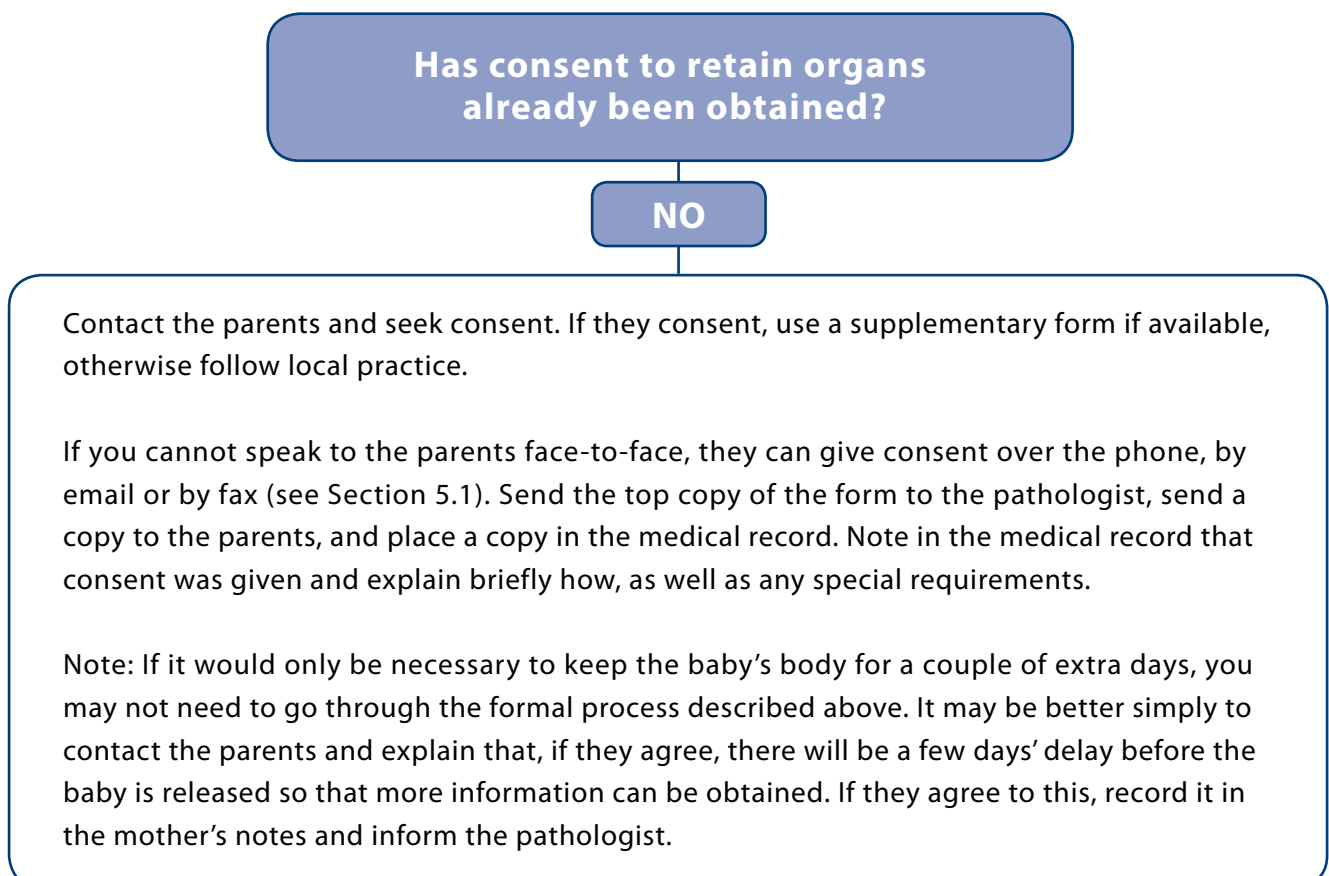
the mortuary. The words "retain" and "retention" have negative associations for some parents and may cause alarm: it is generally better to use "keep" and "kept" when talking to parents.

7.2 If retaining one or more organs for further examination is recommended

► If you know that retention is recommended when you seek post mortem consent



► If retention is only recommended after the post mortem has begun



7.3 Retaining an organ: parents' choices for after the examination

This section outlines the main options but there may be local variations. Before you can discuss retaining an organ with parents you must know what the options and possibilities are in your hospital – see the questions in Section 7.4.

Parents can choose either to delay the funeral until the organ(s) have been returned to the baby's body, or to go ahead with the funeral without waiting for the organ(s) to be returned.

▶ **If the parents decide to delay the funeral until the organ(s) are returned to the baby's body:**

If they are considering whether to see their baby again after the post mortem, you should explain to them that the condition of the body will deteriorate over time. This is not due to the post mortem examination itself but is part of the normal changes that take place after death. They may want to consider saying goodbye beforehand.

▶ **If the parents decide to go ahead with the funeral without waiting for the organ(s) to be returned to the baby's body,** it can take place as soon as the main part of the post mortem is done and the body is released from the mortuary. In this case, the parents will also need to decide what should be done with the organs later. They can:

▶ **Ask the hospital to dispose of the organ(s)** This will be in line with HTA guidance, and, depending on local arrangements, may be by "respectful incineration" (incineration with other human tissue and separate from other hospital waste) or by cremation at a crematorium.

▶ **Have a separate burial or cremation of the organ(s) later** The parents need to know that burial (rather than cremation) may not be possible. If the baby has been buried in a shared grave, it will not be possible to re-open the grave to bury the organ(s). If the baby is in a single grave, permission must be obtained from the cemetery owner to open the grave. If the parents will be arranging the funeral, they will need to discuss the options with the funeral director and ask about any additional costs.

▶ **Donate the organ(s) for research or for training professionals** This is only possible in certain hospitals. Donating organs may be the last thing in parents' minds at this time. However, organs donated for research and education are the basis for doctors' understanding of disease and for preventing similar deaths in future.

If they are considering donation, parents need to know that:

▶ When an organ is used for **training**, names and all other identifying details are always removed first to protect confidentiality. When the organ is no longer needed, it is disposed of in line with the HTA's guidance.

▶ All **research** must be approved by the relevant NHS local or multi-centre Research Ethics Committee.

▶ Names and other identifying details are removed when material is used for research. When the material is no longer needed, it is disposed of in line with the Human Tissue Authority's guidance.

▶ If they agree to an organ being used for research or training, they can change their minds about this at any time in the future. If they do change their minds, they should contact the histopathology department at the hospital.

7.4 What you need to know before you ask parents about retaining an organ

In most hospitals, organs are never or very rarely retained and you will probably not need the answers to these questions.

However, you will need answers to these questions in hospitals where the consent form includes questions about retention and what should be done with the organs afterwards. This includes hospitals with specialist paediatric cardiac or neuropathology units, and hospitals in Northern Ireland.

Each ward or unit where post mortems may be requested should have a *Perinatal post mortem file* containing the Sands document *Information for consent takers: Local practices and arrangements* with the answers to these questions filled in.

If there is no such file, you will need to find out the answers yourself.

- ▶ How long is it likely to be until the further examination of the organ(s) is complete?
- ▶ If the parents want to delay the funeral until the organ(s) have been replaced in the body:
 - ▶ How and where will the baby be kept during this time?
 - ▶ Will it be appropriate for the parents to see their baby again before the funeral?
- ▶ If the parents want the hospital to dispose of the organ(s), what are the local arrangements and options for this?
- ▶ If the parents want to donate the organ(s) for research or for professional training, what are the local arrangements and options for this?

8. Research evidence for the benefits of a post mortem examination

The information in this section will be helpful for your discussions with parents. It is very important that everyone who discusses post mortems with the parents gives consistent information about the benefits.

8.1 Post mortem examination after a stillbirth

Post mortem examination, placental examination and cytogenetic analysis are the most valuable investigations available after a stillbirth. A recent large study of almost 1,200 stillbirths where a post mortem was done, found that it helped to determine the cause of death in 72% of cases; placental examination helped to determine the cause of death in 95% of cases; and cytogenetics in 29% of cases (Korteweg et al 2012).

For some stillbirths there is a single readily identifiable cause of death (eg, placental abruption or severe congenital anomaly) but often the cause is complex and multifactorial. Sometimes several conditions occur simultaneously and contribute to the death so it may not be possible to determine a single cause. There may be interactions between maternal, fetal and placental factors. In many cases there are also conditions that are risk factors rather than a cause of death, for example, diabetes, smoking and obesity (Silver 2011).

Flenady (2011) reported that placental pathology accounted for one in four stillbirths and was contributory or causal in a further half; infection was the second largest category causing 12% of stillbirths; cord problems caused 9% and contributed to stillbirths in a further 8%; congenital anomalies caused 6% and were contributory in a further 5%; and maternal conditions caused 7% of stillbirths and were contributory in 24%. The proportion of unexplained stillbirths was still 30%, but this included many with incomplete investigations. The study was of almost 1,000 babies stillborn at or after 22 weeks and used the CODAC classification system www.codac-classification.org. Other studies report similar figures.

A post mortem following a stillbirth:

- ▶ Provides new information that changes the diagnosis in between 9% and 34% of stillbirths (Cernach et al 2004, Kock et al 2003, Faye-Petersen et al 1999, Cartlidge et al 1995).
- ▶ Provides some additional information in 22% of stillbirths (Kock et al 2003).
- ▶ Confirms the clinical diagnosis in between 49% and 58% of stillbirths (Kock et al 2003, Faye-Petersen et al 1999). Confirmation of clinical diagnosis should not be regarded as a “negative” outcome.

Compared with post mortem examination of a stillborn baby and examination of the placenta, other investigations, including maternal blood tests, identify a cause in less than 20% of cases (Downe et al 2012).

8.2 Examination of the placenta after a stillbirth

The proportion of “unexplained stillbirths” is significantly lower when the placenta is examined (odds ratio 0.17, 95% confidence interval 0.04–0.70) (Heazell and Martindale 2009).

Histopathological examination of the placenta after stillbirth showed abnormalities in between 58% and 84% of examinations (Kidron et al 2009, Hayati et al 1998). Of the abnormalities that were found, 64% were known to contribute to fetal death (Hayati et al 1998).

In those cases where placental abnormalities were identified, these abnormalities were the only identified cause of death in between 15.7% and 19.2% of cases (Bonetti et al 2011, Heazell and Martindale 2009).

8.3 Post mortem examination and placental examination after a neonatal death

In a study of babies born alive before 28 weeks’ gestation and dying at less than 28 days, a post mortem provided new information about the cause of death in 79% of cases and significantly changed the diagnosis in 28% of cases (Elder and Zuccollo 2005).

In a study of term infants with known perinatal asphyxia, all the post mortems confirmed evidence of hypoxia. Significant new information was found in 62.5% of neonatal deaths (Elder et al 2005).

Examination of the placenta after a neonatal death can also be very helpful (Tellefsen et al 2011). It is relatively straightforward after a very early neonatal death when the placenta is still available. Many hospitals also examine the placentas of all babies who require admission to the neonatal unit.

8.4 Post mortem examination after a termination for fetal abnormality

Most terminations for fetal abnormality are done after abnormalities have been identified by ultrasound or cytogenetics.

Post mortem examination is particularly useful in differentiating conditions that have the same ultrasound appearance but different risks of recurrence, for example, infantile polycystic kidney disease (recurrence rate 25%) and cystic renal dysplasia (recurrence rate 3%).

Studies comparing ultrasound diagnosis with diagnosis at post mortem found complete agreement in 47% to 72% of cases. In about 28% of cases a post mortem provided major additional information and, in a further 13% of cases, it provided a definitive diagnosis (Johns et al 2004).

A post mortem changed the estimated risk of recurrence in 27% of cases (Boyd et al 2003).

8.5 Raising post mortem rates

Inadequate knowledge regarding the underlying causes of stillbirth hinders progress in reducing high UK stillbirth rates (Heazell et al 2012).

A recent study in Edinburgh (Stock et al 2010) found that post mortem rates following a stillbirth increased following a number of interventions:

- ▶ Specialist perinatal pathologists relocated to the same site as the obstetric unit. This enabled more timely post mortems and quicker returns, which were important for parents. It also facilitated attendance by doctors and midwives at post mortems, and enabled perinatal pathologists to participate in case discussions, meetings and teaching.
- ▶ A formal programme of education for doctors and midwives on the value of a post mortem, and encouragement to attend post mortems.
- ▶ The requirement that authorisation for post mortems is always sought by senior staff.

9. The Human Tissue Act 2004 and the Human Tissue (Scotland) Act 2006

The Human Tissue Act 2004

This Act does not contain a statutory definition of a post mortem examination.

Section 1 of the Human Tissue Act 2004 requires consent for removal, use or storage of a deceased person's body or of relevant material from the body (that is, material which consists of or includes human cells), where the purpose of removal, use or storage is any of the purposes set out in Schedule 1. These are:

- ▶ Determining the cause of death
- ▶ Establishing after a person's death the efficacy of any drug or other treatment administered to him
- ▶ Obtaining scientific or medical information about a living or deceased person which may be relevant to any other person (including a future person)
- ▶ Research in connection with disorders, or the functioning, of the human body
- ▶ Clinical audit
- ▶ Education or training relating to human health
- ▶ Performance assessment
- ▶ Public health monitoring
- ▶ Quality assurance

The Human Tissue (Scotland) Act 2006

Part 2, Section 23 of this Act defines a post mortem examination as the examination of the body of a deceased person involving its dissection and the removal of organs, tissue sample, blood (or any material derived from blood) or other body fluid which is carried out for any or all of the following purposes —

- (a) providing information about or confirming the cause of death;
- (b) investigating the effect and efficacy of any medical or surgical intervention carried out on the person;
- (c) obtaining information which may be relevant to the health of any other person (including a future person);
- (d) audit, education, training or research.

10. References and sources of further guidance

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11. Useful addresses

Human Tissue Authority

www.hta.gov.uk

Tel: **020 7269 1900**

Enquiries: enquiries@hta.gov.uk

Charities that offer support to parents whose baby dies and to the health professionals who care for them

Sands, the stillbirth and neonatal death charity

Support, advice and information for anyone, including health professionals, affected by the death of a baby before, during or shortly after birth.

www.sands.org.uk

Helpline: **0808 164 3332**

Email: helpline@sands.org.uk

ARC – Antenatal Results and Choices

Non-directive support and information for expectant and bereaved parents before, during and after antenatal screening, and also support and information for health professionals.

www.arc-uk.org

Helpline: **0845 077 2290** or **020 7731 7486**

Email: info@arc-uk.org

Bliss – the special care baby charity

www.bliss.org.uk

Support, advice and information for families of babies in intensive care and special care, including bereaved families, and also support and information for health professionals.

Helpline: **0500 618 140**

Email: enquiries@bliss.org.uk

Child Bereavement UK

Supporting families and educating professionals when a child dies and when a child is bereaved.

www.childbereavement.org.uk

Support and information: **0149 456 8900**

Email: support@childbereavementuk.org

Miscarriage Association

Support and information for those affected by pregnancy loss, including health professionals. www.miscarriageassociation.org.uk

Helpline: **01924 200799**

Email: info@miscarriageassociation.org.uk

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Whilst every care is taken providing information, please note that it is of general nature and that readers should seek professional or expert advice as appropriate to their specific circumstance. Sands does not accept any liability, including liability for any error or omission.

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Sands

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Sands message boards www.sandsforum.org

Sands publications order online at www.sands.org.uk/shop

Registered as a charity in England and Wales (299679) and in Scotland (SC042789)

Text written by Alix Henley and Judith Schott, 2012

About Sands

Sands, the stillbirth and neonatal death charity, was founded in 1978 by a small group of bereaved parents.

Since that time, we have supported many thousands of families whose babies have died, offering emotional support and information. Today Sands operates throughout the UK and focuses on three key areas:

We support anyone affected by the death of a baby

Bereavement support is at the core of everything we do. Some of the services that we offer include:

- ▶ Helpline for parents, families, carers and health professionals
- ▶ UK-wide network of support groups run by trained befrienders
- ▶ Online forum and message boards enabling bereaved families to connect with others
- ▶ Website and a wide range of booklets, books and other resources.

We depend on the extraordinary energies of our supporters to raise the vital funds that we need to deliver the wide range of services that we offer.

We work in partnership with professionals to try to ensure that bereaved parents and families receive the best possible care

We produce a wide range of online and printed resources to support professionals to provide sensitive, empathic bereavement care, focused upon the needs of parents. We also deliver high quality, evidence-based, accredited training workshops in bereavement care to professionals across the country, providing the latest information and support in working with bereaved parents.

We promote and fund research that could help to reduce the loss of babies' lives

We believe many babies' deaths could be prevented with better care and information. We raise vital funds for research and work with clinicians and experts to understand why babies die and how to save lives. We also provide policy expertise at government level and campaign to make addressing the tragedy of too many baby deaths a policy priority nationally and locally.

If you would like any further information or support please contact us or visit our website.

Support:

t: 0808 164 3332

e: helpline@sands.org.uk

Enquiries:

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