Adopting the Sands *Post mortem consent form* in your hospital, trust or health board

Information for decision makers
The decision to use the Sands form, and the precise details of what is included, should be taken by the local hospital, trust or health board in discussion with representatives of perinatal and paediatric pathologists, obstetricians, neonatologists, bereavement midwives and other key stakeholders.

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A. Introduction and the benefits of the Sands Post mortem consent form

Sands has developed its Post mortem consent form over a period of two years, in consultation with health professionals across the United Kingdom – including obstetricians, neonatologists, perinatal and paediatric pathologists, midwives, neonatal nurses, anatomical pathology technologists, clinical geneticists and mortuary managers – and with the Human Tissue Authority (HTA), as well as with parents.

The form is part of the Sands Post mortem package which also contains an information booklet for parents and a guide for consent takers (see F below for more about these). The package was developed with funding support from the Department of Health.

The Sands form:
- is easy to use, supports consent takers and ensures clarity for pathologists
- meets the HTA’s requirements, including its ruling on consent to retain organs
- models sensitive language, and contains a level of detail that is acceptable to most bereaved parents
- enables parents to make decisions about a post mortem without adding unnecessarily to their distress.

A standard consent form used widely in the UK will also benefit:
- pathology departments that carry out post mortems for several hospitals
- staff who move hospitals and currently have to deal with a series of different forms
- trainers who train staff from different hospitals
- professional organisations that develop national training materials.

For downloadable copies of the form and other documents please go to: www.hta.gov.uk/legislationpoliciesandcodesofpractice/modelconsentforms.cfm

The Sands Post mortem consent form, the supplementary form and the optional insertion to the form – see below – have been developed with and approved by the Human Tissue Authority (HTA), which is responsible in England, Wales and Northern Ireland for ensuring that the Human Tissue Act 2004 is put into practice and for approving post mortem consent forms. However, the form can only be used in England at present.

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

The other material in the package, ie, the Sands Guide for consent takers and Deciding about a post mortem, the Sands information booklet for parents, have also been approved by the HTA and are relevant in all four UK countries.
B. Retaining organs for further detailed examination: when is it necessary to seek consent?

Many existing post mortem consent forms routinely ask bereaved parents to consent to organ retention and disposal. This adds to parents’ distress and leads some to decide against a post mortem, even though they urgently want to know as much as possible about why their baby died and the possible implications for a future pregnancy.

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 released¹.

Because, in most hospitals, organs are never or very rarely retained after the baby is released, the Sands Post mortem consent form does not contain a section on organ retention.

- To cater for the rare occasions in these hospitals when retaining an organ after the baby is released might be recommended, Sands has developed a supplementary form: Consent to further examination of organs for diagnostic purposes (see D below for more).

The supplementary form can be used when it is needed, either at the time when post mortem consent is sought (if, for example, there is a pre-existing diagnosis), or after the post mortem has begun if the pathologist recommends retaining an organ. In the latter case, if the discussion with the parents cannot be face-to-face, it can take place over the phone: consent can be given by phone, email or fax, provided the supplementary form is completed and signed by the consent taker. The consent taker should note in the medical record that consent was discussed and given, explain why the discussion was not face-to-face, and note any special points.

If the parents do not consent, this should also be noted in the medical record.

Because retaining an organ after the baby’s body is released is rare, consent takers in most hospitals will never need to use the supplementary form.

- In a few UK hospitals, especially those with specialist neonatal cardiology or neurology research units, or where it is customary to release the baby’s body within two or three days for the funeral, organs are more often retained.

To cater for this, Sands has developed an Optional section on retaining organs. This can be inserted into the Sands Post mortem consent form before it is printed (see E below for more).

- However, because routinely discussing organ retention and disposal with parents causes them additional distress and often turns out to have been unnecessary, Sands recommends that hospitals, trusts and health boards only insert the Optional section after very careful consideration.

¹This statement covers England, Wales and Northern Ireland. The situation in Scotland is currently under review.
From the parents’ point of view, it is better to use the supplementary form described above, as and when it is needed.

- For more about seeking consent to retain organs after the baby’s body is released, please see the Sands Guide for consent takers, on the HTA website.

# Printing the forms

## C. The Sands Post mortem consent form

For many parents, their copy of the consent form is one of the few physical mementoes they have of their baby. Consent forms should always look good and be professionally printed.

In most hospitals, this is the only form you need. It can be formatted either as A4 sheets which are photocopied after completion, or as an A3½ sheet with carbon copies (for more on the A3½ format, see below).

### Before you print the form

- Please delete the box on the front page.
- Sections 1 to 7, which make up the core of the form, have been approved by the HTA and no substantive changes should be made to the wording. Any substantive changes must be checked with the HTA.

But:

- The second and third options in Section 4 can be deleted if they are not relevant to your hospital.
- The Optional section on retaining organs can be inserted after Section 4 of the form, if retaining an organ after the baby’s body is released from the mortuary is routinely or frequently recommended at your hospital – see B and E for more about this.

### Local additions

- There is space for the hospital name and/or the name of the trust/health board (or whatever is required), plus the NHS logo, on the front page.
- If it is absolutely essential to insert additional content to the main body of the form to reflect local provision, please check that the language is clear, sensitive and helpful, and the order of items is logical. If you would like to discuss additions, please email [alix.henley@uk-sands.org](mailto:alix.henley@uk-sands.org)
- Some of the information boxes in the demographics table on Page 2 of the form could be deleted, though it is important to check that this information is not needed by the staff who are in contact with the parents.
- You may want to add local instructions or information, eg, phone numbers and contact details, to the notes in Section 8, or on the front page. If you do, please remember to check and delete any existing instructions in Section 8 that are no longer relevant or that conflict with those you have added. (If you have added notes to Section 8, please check that the reference in Section 2 of the form – “See Section 8 Item 6 for more information” – is still correct.)
For more information and FAQs about the Sands Post mortem consent form please go to the HTA website.

**Printing A4 or A3½ formats**

Some units prefer A4 forms and photocopy them after completion; others prefer A3½ forms with two carbon copies.

**To use an A4 format** Print the Sands Post mortem consent form as it is laid out.

**To use an A3½ format** The three content pages (2 to 5) of the Post mortem consent form should all be on one side of the sheet of paper. On the other side, Page 1 (title page) should be the right-hand panel and Section 8 (Notes for the consent taker) should be the central panel.

To get the content of the form (Pages 2 to 5) onto an A3½ sheet you will need to make a few changes:

- The footer is not needed and can be deleted.
- Some of the boxes in the demographics table on Page 2 of the form can be deleted, though it is important to check that this information is not needed by the staff who are in contact with the parents.
- If organs are never donated for training or research in your unit, Section 4 can be deleted. (Note that this will change the section numbering at the end of the form.)
- You may need to reduce the spaces between the sections.

**D. The supplementary form:**

*Consent to further examination of organs for diagnostic purposes*

You need this supplementary form if retaining an organ after the baby’s body is released from the mortuary is occasionally (or rarely) recommended at your hospital. The form should only be used when retaining one or more organs is specifically recommended.

- There is space on Page 1 for the hospital name and/or the name of the trust/health board (or whatever is required), plus the NHS logo.
- If organs cannot be donated for professional training or research at your hospital, you can delete the final option on Page 1 of the form and the paragraph that follows it.
- Any other substantive changes to the content on Page 1 of this form must be checked with the HTA.
- If it is absolutely essential to insert additional content to the main body of the form to reflect local provision, please check that the language is clear, sensitive and helpful, and the order of items is logical. If you would like to discuss additions, please email alix.henley@uk-sands.org
Add any local instructions or information to the notes on Page 2 of the form. Please remember to delete any existing instructions that are no longer relevant or that conflict with those you have added.

Please delete the box on Page 2 before you print the form for use with parents.

E. The Optional section on retaining organs

You may want to insert this Optional section into the standard form if retaining an organ after the baby’s body is released from the mortuary is routinely or frequently recommended at your hospital. Note that the form will no longer fit into an A3½ format if the optional section is added.

- Insert the Optional section on retaining organs into the Sands Post mortem consent form as Section 5. You will need to change the numbering of the subsequent sections.
- Delete Item 9 in Section 8.
- Please delete the box at the bottom of the section.
- Follow the other instructions for the Sands Post mortem consent form in C above.
- You will not need the supplementary form: Consent to further examination of organs for diagnostic purposes.

F. The other items in the Sands Post mortem consent package

In addition to the Post mortem consent form discussed above, the package contains:

- A booklet, Deciding about a post mortem: Information for parents. You can download a copy from the Sands website www.uk-sands.org/Support You can order copies from the shop shop@uk-sands.org To order by phone, please call: 0845 6520 445.
- The Sands Guide for consent takers. This is written 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. It can also be used as a basis for consent taker training. Downloadable from the HTA website.
- Compiling local information for post mortem consent takers Excerpted from the Guide for consent takers. It lists all the local information that consent takers need when discussing a post mortem with parents. The information should be entered and kept on wards and units where perinatal post mortems may be requested. Downloadable from the HTA website.