

Sands Position Statement

Post mortem examination after a late miscarriage, stillbirth or neonatal death

All parents whose baby dies before, during or shortly after birth should be offered the opportunity to discuss giving consent or authorisation for a post mortem examination. The burning question for most parents is, "Why did our baby die?". A post mortem examination offers the best chance of identifying factors that contributed to the death. It may also provide information that could be important if, in the future, parents might want to have another baby. In addition, the findings of post mortem examinations can contribute to research and help to reduce the high numbers of babies who die around the time of birth.

However, post mortem rates in the UK are low, despite clear evidence that they often provide new or additional information (Downe et al 2012). Research shows that healthcare staff tend to underestimate the benefits of post mortems. Some avoid seeking consent for fear of adding to the distress that parents are already feeling, and some make assumptions about who might refuse a post mortem on religious grounds (Heazell et al 2012). Some are also deterred by long and unnecessarily detailed forms that add to parents' distress.

Some parents refuse a post mortem because they want their baby to be left in peace, or because they cannot bear to think about what the procedure involves. Some do not want to delay the funeral, especially if a post mortem would involve transfer to another hospital. However, research shows that twice as many parents later regretted refusing a post mortem compared with those who consented to one (Heazell et al 2012). It is therefore essential that staff offer all parents the opportunity to discuss a post mortem and that they explain the potential benefits so that parents can make an informed choice.

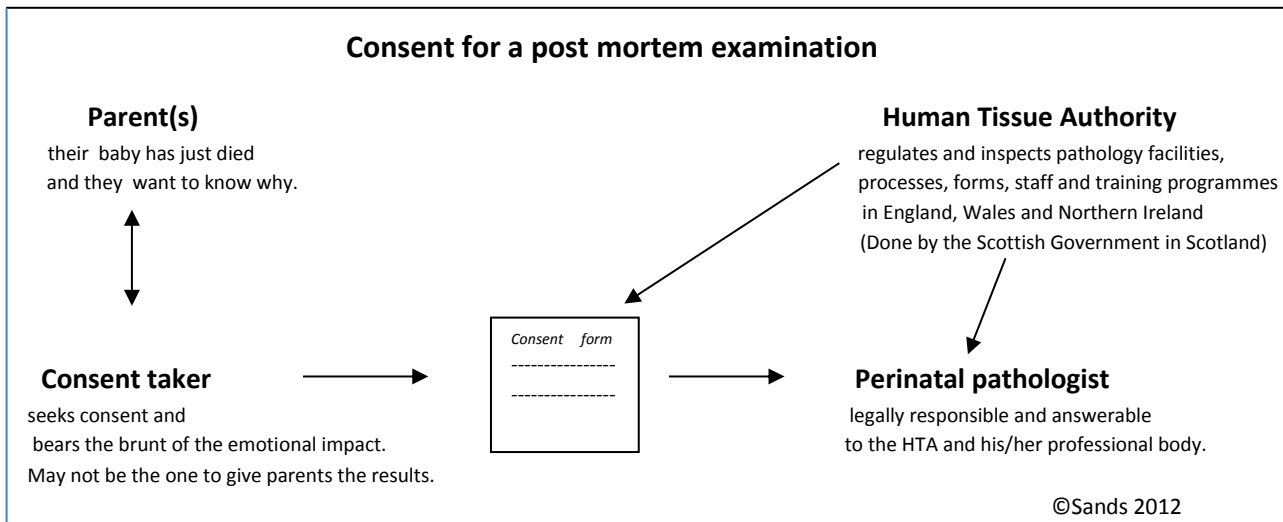
The complications of post mortem consent

Some aspects of seeking consent for a post mortem make it particularly complicated and difficult.

- A post mortem is a complex procedure and parents who are already distressed and traumatised have to consider several different options.
- Consent is sought by someone who is not a pathologist. Normally consent for surgery or treatment is sought by a member of the team that will carry out the procedure. The "contract" is between patient and doctor. The "contract" to perform a post mortem is between parents and pathologist and they are very unlikely to meet or communicate. Consent is sought on the pathologist's behalf by staff who may never have met him or her, and who will not be involved in the post mortem.

However it is the pathologist who would be held responsible by the Human Tissue Authority (in England, Wales and Northern Ireland, and by the Scottish Government in Scotland) and by their professional body if they do anything that the parents have not agreed to. It is therefore essential that consent forms are absolutely clear and that consent takers are properly informed and trained. Another barrier to giving consent is the length and complexity of some consent forms. Current forms vary widely in England. (Scotland, Northern Ireland and Wales each has their own unique consent form which is used by all the units in each country. The term "authorisation" is used in Scotland.)

Consent for a post mortem examination



Sands believes that consent forms should contain essential questions only and that they should be written clearly and simply; that parents should have access to good clear back-up information; and that all consent takers should have guidance on what they need to know in order to discuss a post mortem with parents, and on how to approach the parents. To address these issues, Sands has produced the Sands *Post mortem consent package* in consultation with parents, health care staff – including perinatal and paediatric pathologists, obstetricians, neonatologists, paediatricians, midwives, anatomical pathology technologists and clinical geneticists – and the Human Tissue Authority. The package consists of:

- a consent / authorisation form which is acceptable to all the stakeholders
- a booklet *Deciding about a post mortem: information for parents*
- a *Guide for consent takers*

The *Post mortem consent form* can currently be used in England. Separate consideration is being given in Scotland to a similar form which complies with the Human Tissue (Scotland) Act 2006. Sands hopes that new forms, based on the Sands template, will eventually be available in Wales and Northern Ireland. Both the *Guide for consent takers* and *Deciding about a post mortem*, the information booklet for parents, are relevant throughout the UK. The form and the *Guide for consent takers*, as well as more information about the package, are available to download from the HTA website:

<http://www.hta.gov.uk/licensingandinspections/sectorspecificinformation/postmortem/perinatalpostmortem.cfm>

Printed copies of the booklet *Deciding about a hospital post mortem examination: Information for parents* are available from Sands. The booklets are free but there will be a charge for postage and packing. Email orders: shop@uk-sands.org, telephone orders: 0845 6520 445, or online: <http://www.uk-sands.org/Shop.html>. A PDF can also be downloaded from the Sands website: <http://www.uk-sands.org/support>.

References

Downe S, Kingdon C, Kennedy R, Norwell H, McLaughlin MJ, Heazell AE (2012) Post-mortem examination after stillbirth: views of UK-based practitioners, *Euro J Obstetric Gynecol Reprod Biol* **162**:33-37

Heazell A, McLaughlin MJ, Schmidt E, Cox P, Flenady V, Khong T, Downe S. A difficult conversation? (2012) The views and experiences of parents and professionals on the consent process for perinatal post mortem after stillbirth *BJOG* **119**:987-997