

## **Sands position statement**

### **Post mortem examination after a pregnancy loss or death of a baby before, during or shortly after birth**

All parents who experience a pregnancy loss or whose baby dies before, during or shortly after birth should be offered the opportunity to discuss having a post mortem examination of their baby. Many parents want to know why their baby died and a post mortem examination offers the best chance of identifying factors that contributed to the baby's death. Parents may also want information that could be important for other children or if they decide to have another baby. The findings of post mortem examinations can also rule out causes and contribute to research that helps to prevent babies' deaths and reduce the number of babies who die around the time of birth.

In some areas of the UK, post mortem rates are low despite clear evidence that post mortems often provide new or additional information (Downe *et al.* 2012). Some healthcare staff may underestimate the benefits of post mortems. One study found that some staff may also avoid seeking consent for fear of adding to parents' distress and that some staff do not offer this option as they assume that certain parents may refuse a post mortem on religious grounds (Heazell *et al.* 2012). Some staff may also be deterred by long, complicated post mortem consent forms.

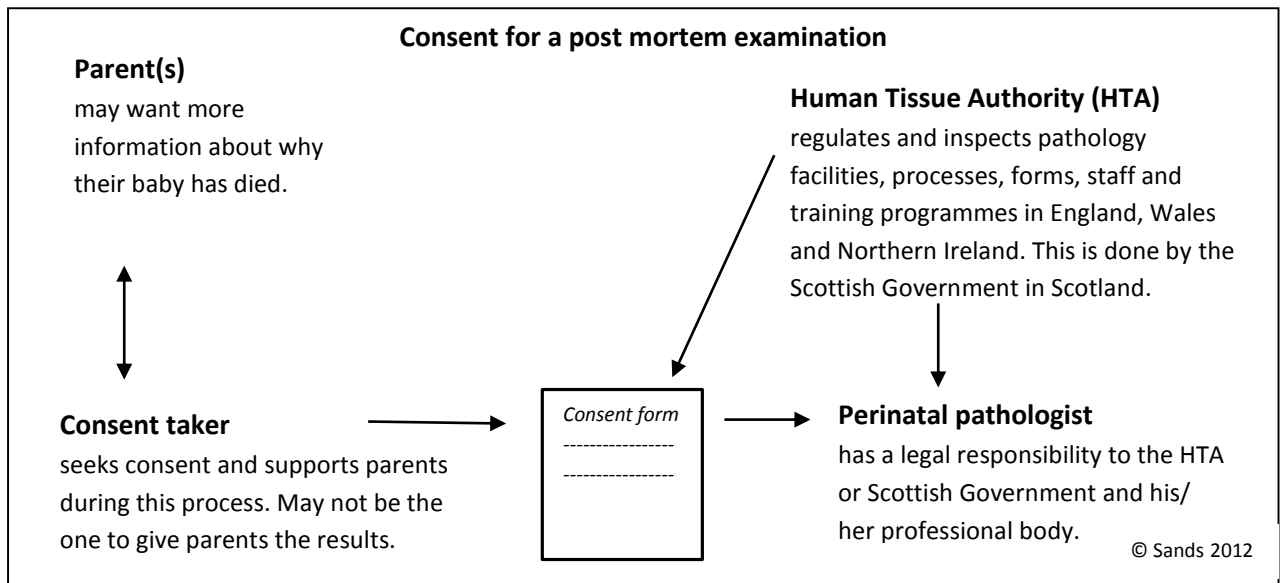
Additionally, some parents may feel that a post mortem examination is not necessary (Redshaw *et al.* 2014). Other parents might refuse a post mortem because they want their baby to be left in peace or they do not want to think about what the procedure involves. Some parents may not want to delay their baby's funeral, especially if a post mortem would involve transfer to another hospital. Despite this, it is 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. Parents may be more likely to regret not having a post mortem examination of their baby than having these investigations (Heazell *et al.* 2012). However, parents' decisions must be respected regardless of their choice.

#### **Seeking consent for a post mortem**

It is important that staff explain the options available to parents in a sensitive manner and in language that parents can understand. They may need to repeat information more than once and should understand the process if parents want more details or have questions.

Staff may find some aspects of seeking consent for a post mortem complicated or difficult, particularly if parents are distressed. Consent is often sought on a pathologist's behalf by someone who is not a pathologist and who will not be involved in the post mortem. 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. In this case, the "contract" to perform a post mortem is between parents and a pathologist although they are unlikely to meet or communicate with each other

Despite this, it is the pathologist who would be held responsible by the Human Tissue Authority (HTA) in England, Wales and Northern Ireland, the Scottish Government in Scotland and by their professional body if they do anything that the parents have not agreed to. Therefore, it is essential that consent forms are clearly completed and that consent takers are properly trained.



The consent forms used in England vary widely. Scotland, Northern Ireland and Wales have their own specific consent form which is used by all the units in each country. The term “authorisation” is used instead of consent in Scotland. The length and complexity of some consent forms may be a barrier to obtaining parents’ consent for a post mortem examination.

Consent forms should contain essential questions only and should be written clearly and simply. Parents should also be given a copy of this form that provides them with clear information about what they have authorised. Additionally, all consent takers should have guidance on what they need to know in order to sensitively discuss a post mortem with parents and support parents through this process. To address these concerns, Sands has produced the Sands *Post mortem consent package* in consultation with parents, healthcare staff (including perinatal and paediatric pathologists, obstetricians, neonatologists, paediatricians, midwives, anatomical pathology technologists, clinical geneticists) and the HTA. 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 soon 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 is a charge for postage and packing. Email orders: [shop@uk-sands.org](mailto:shop@uk-sands.org), telephone orders: 0845 6520 445, or online: <http://www.uk-sands.org/Shop.html>. A PDF of the booklet 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

Redshaw M, Rowe R, Henderson J (2014) Listening to Parents after stillbirth or the death of their baby after birth. Oxford: National Perinatal Epidemiology Unit. Available at <https://www.npeu.ox.ac.uk/listeningtoparents>

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