

A UK-wide consent package for perinatal post mortems



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Post mortem rates in the UK following either stillbirth or neonatal death are low, despite clear evidence that a post mortem commonly provides unique and important information for both families and the clinical team caring for them. Findings at post mortem examination often corroborate the ante mortem clinical diagnosis, but in a significant proportion of cases they also identify previously unsuspected, clinically important information, relating to both the underlying diagnosis and, in the case of neonatal death, to treatment administered. For example, between 10 and 35% of post mortems after a stillbirth provide information that changes the diagnosis and a further 22% provide significant additional information¹⁻³. In neonatal cases, over 50% of post mortems provide significant new information^{4,5}.

There are numerous reasons for the fall in post mortem rates. Rates fell sharply after the organ retention scandal in 2000; although the negative press still deters many clinicians, it is not usually a factor for parents. Other factors that may be keeping rates low include a change in clinicians' views of the importance of the post mortem, coupled with the increased availability of high definition imaging (eg magnetic resonance imaging, MRI). MRI is seen by some as the non-invasive equivalent of a post mortem, although it clearly cannot supersede histological examination. Also, clinical staff often want to limit parents' emotional distress immediately following their baby's death. Other significant barriers for clinicians include religious or cultural issues, staff workload, lack of rapport with the parents and significant delays in producing a final report due to a national shortfall in perinatal pathologists. Parents are most likely to be deterred from giving consent by emotional distress. They are also likely to be deterred by the need to send their baby to a different unit for the post mortem and by excessive delays in obtaining results, with a consequent delay in moving towards closure for their loss⁶.

Talking to parents about consent for a post mortem examination is a complex process. A variety of personnel may be involved including obstetricians, midwives, neonatologists, neonatal nurses and bereavement staff. Perinatal pathologists, who are most able to explain the benefits of the examination, are least likely to be involved. Discussions about consent may involve

clinicians sharing their uncertainty about the underlying diagnosis, with the potential for implying uncertainty about the appropriateness of preceding management, particularly following a fresh stillbirth or neonatal death. Many staff lack proper training and experience in seeking consent. Areas of particular difficulty for staff may concern decisions regarding limiting the extent of the post mortem, testing for conditions with a genetic component, delay in returning specific organs while further specialist opinion is sought (see below) and the disposal of tissue following the examination. Lengthy forms and poor written information for families further hamper the consent process.

It is essential that documentation pertaining to the post mortem examination provides clear information to parents at this extremely distressing time. The process of discussing consent should not add unnecessarily to a family's pain and the consent form itself should be concise while making it sufficiently clear to the family what it is they are consenting to. Lengthy, over-detailed forms make it less likely that consent takers will initiate the process.

It is against this background that the launch of a package of documents around obtaining consent for post mortem is timely and welcome. Sands, the stillbirth and neonatal death charity, has consulted widely over the last two years with the Human Tissue Authority (HTA) and with a large number of health professionals from all disciplines across the UK who are involved in any aspect of the post mortem process. Sands also consulted a number of bereaved parents about their experiences of post mortem and post mortem consent when developing the new material.

Preliminary discussions with health professionals revealed large differences in both the pathway and documentation for obtaining consent for a post mortem across the UK. These differences cause problems and confusion, particularly for staff who move between hospitals and for pathologists who receive babies from several hospitals. They also complicate consent training across hospitals.

The Sands post mortem consent package consists of a:

- consent form
- guide for consent takers
- booklet for parents (FIGURE 1)

The parents' booklet will be offered free to all

UK hospitals and to individuals who request it. It will also be available for download from the Sands website.

The consent form and the consent takers' guide will be available on the HTA's website. Clinicians who use the Sands post mortem consent form may notice a number of changes to the form they are used to. The new form is shorter and contains less detail than many current forms. This is in response to parents' strong statements that, while they want to know why their baby died, the vast majority do not want detailed accounts of what will happen to their baby. Those who do want more information can ask the consent taker. The HTA confirms that it is not necessary to seek consent to retain organs if they will be replaced before the baby is returned for the funeral. The package contains a second form to be used on those rare occasions when retention of an organ is recommended.

The Sands package has been approved by the British Association of Perinatal Medicine (BAPM). The Sands consent form has also been approved by the 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. Due to administrative

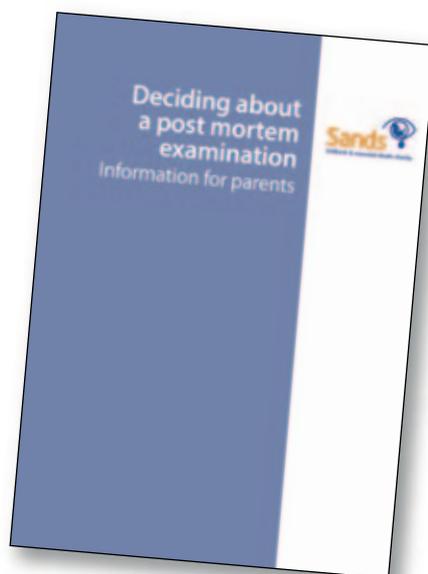


FIGURE 1 The Sands booklet for parents.

differences, the form can only be used in England at present. Separate consideration is being given in Scotland to a similar form that complies with the Human Tissue (Scotland) Act 2006. Sands will review the form after a period of time and will seek clinicians' opinions on possible changes. The guide for consent takers and the parents' information booklet are relevant throughout the UK.

Sands hopes that all UK hospitals will eventually use its parent-friendly, approved consent form so that the

process of seeking consent can be simplified and less distressing for parents. Use of a standard form throughout the UK should avoid the confusion and errors caused by current variations. Sands hopes that the post mortem consent package will make a real difference to parents and, by increasing post mortem rates, will also help research into preventing neonatal death.

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