

Specialist nurses boost parental willingness to consent to post-mortem research on children

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Parents are mostly willing to consent to post mortem research on their children, providing they are approached by specialist nurses, experienced in bereavement and family counselling, suggests a small study published ahead of print in the *Archives of Disease in Childhood*.

Post mortem research is crucial to understanding cases of sudden, unexpected death in children.

But following the Alder Hey organ retention scandal, in which children's tissue was retained for research without consent, recent changes to legislation and coroners' rules have made it difficult to carry this out.

Most cases of unexplained death in children are automatically referred to the coroner, who cannot authorise tissue to be kept for research without explicit [parental consent](#).

But many coroners are neither trained, nor have the resources, to seek parental consent, and contacting newly bereaved [parents](#) to get it is often seen as unethical, say the authors. As a result, tissue is disposed of, as it must be by law, and so lost to research.

In a bid to reverse this trend, researchers at the Institute of Child Health and Great Ormond Street Hospital in London, piloted a telephone consenting system as part of a Department of Health "less invasive [autopsy](#)" study.

Before the post mortem, a [family liaison](#) sister, experienced in dealing with bereaved families, contacted 32 sets of parents, whose children were aged between one day and seven years when they died.

On average, she approached parents two days

after their child's death, to ask if they would consent to non-invasive (MRI) imaging of their child.

One set of parents refused; three asked for further time to consider the request, but then agreed on the second call, and the remainder all agreed first time around.

Their main reasons given for doing so, were the chance to help other parents in the future, and the importance of post mortem research. Agreement was also subsequently obtained in writing.

"Contrary to popular belief that newly bereaved parents would react angrily to such an approach, we found that most parents viewed the process positively and did not have any objections to the telephone approach," comment the authors.

"In fact, it appears that that the opportunity to discuss the post mortem process soon after death with a bereavement nurse was beneficial to [them]" they add.

But of the 20 coroners approached to take part in the study, two declined and 15 refused. And although 76 cases from 38 different coroners were eligible, permission to contact the parents was only granted in 32 cases.

This highlights the need for a unified national approach to address this issue, say the authors.

Source: British Medical Journal ([news](#) : [web](#))

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