

21 January, 2013

Sands launches new *Post Mortem Consent Package*

Sands, the stillbirth and neonatal death charity, today launches the *Sands Post mortem consent package* developed to provide information and guidance about post mortems for health professionals seeking consent, and for bereaved parents whose baby has died before, during or shortly after birth.

The package, developed in consultation with the Human Tissue Authority (HTA) includes; a new *Post mortem consent form*, a *Guide for consent takers*, and a support booklet for parents: *Deciding about a post mortem: Information for parents*.

This new package has been developed over a 2 year period, in close consultation with health professionals and bereaved parents across the United Kingdom, to make it easier for health professionals and parents to discuss a post mortem and to ensure that parents can make an informed choice as to whether to have a post mortem examination of their baby.

“When you have a baby who dies it seems that there’s nothing positive, and you just have to try to find something that might be positive. For us, it was that we got an answer about why, but also, knowing that somebody else may gain from that.” Bereaved Mum.

17 babies are stillborn or die shortly after birth every day in the UK and Sands also hopes that, by increasing the perinatal post mortem rate, which is currently low in the UK, this package will provide information that could help reduce the numbers of late miscarriages, stillbirths and neonatal deaths in the future.

Why is this new post mortem consent package needed?

Every year in the UK over 6,500 babies die just before, during, or soon after birth and a post mortem examination is the single most useful investigation in providing information for parents about why their baby died (Downe et al 2012). However, perinatal post mortem rates in the UK are low.

Why are post mortem rates so low and why does this matter?

Post mortem rates for stillbirths in the UK fell from 55% in 2000 to 45% in 2009, the main fall being between 2000 and 2002 following adverse publicity about organ retention. Post mortem rates for neonatal deaths in the UK fell from 29% in 2000 to 18% in 2009.

The low post mortem rate means that many parents are left with unanswered questions about why their baby died, and about what might be done in subsequent pregnancies to avoid further deaths. It also means that there is little information on which to base measures and policies that might reduce the UK's high perinatal mortality rate. (A recent international analysis in *The Lancet* (2011) placed the UK's stillbirth rates 33rd out of 35 similar high-income countries.)

Recent research shows that a range of factors are contributing to this low post mortem rate. A significant number of health professionals underestimate the value of a perinatal post mortem and may not discuss a post mortem with parents (Heazell et al 2010). Many professionals also, understandably, find such discussion very difficult and fear that it will add to parents' distress (Heazell et al 2012). Some professionals are deterred by long and detailed consent forms which also often add to grieving parents' distress.

Dr Alex Heazell, clinical lecturer, Maternal and Fetal Health Research Centre, University of Manchester, who has worked closely with Sands to develop the new package comments: "The consent process has actually become a barrier to post mortem consent. We know from recent research* in Scotland that the quality of the consent process is an important factor in increasing post mortem rates which is why this new package is so urgently needed."

Aims of the post mortem package

Alix Henley, Sands Advisor and co-author of the Sands post mortem package: “The overall aim of this package is to improve the quality of the consent process to ensure that all parents are given the option of discussing whether to have a post mortem examination of their baby.

“The main aim of any post mortem is to help parents understand why their baby died and to try to ensure the best care in a subsequent pregnancy. By using this package health professionals can ensure that parents are in a position to make a fully informed decision as to whether to have a post mortem examination of their baby.”

“We hope that the post mortem consent package will also be an invaluable resource for health professionals, as it provides practical help and guidance for those undertaking the difficult task of discussing a post mortem with bereaved parents.”

What does the post mortem package include?

- ***Post mortem consent form.*** This HTA-approved form aims to make discussing post mortem consent less distressing for bereaved parents, and easier for consent takers. The form is easy to use, supports consent takers and ensures clarity for pathologists. It models sensitive language for consent takers, and contains a level of detail that is acceptable to most bereaved parents, enabling them to make decisions about a post mortem without adding unnecessarily to their distress. The form has the support of the Royal College of Pathologists and of the British and Irish Paediatric Pathologists Association (BRIPPA).

Parents who have read the new consent form agree it is needed: “I would be far happier using this new form than the one we were asked to complete when our son died. It was very medical and long..... All we wanted to do was say yes so that we could try and get some answers, yet we had to go through all the detail.” Bereaved Mum

- Sands ***Guide for consent takers*** supports staff who undertake the difficult task of discussing a post mortem with bereaved parents. It has been written for staff who are not used 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.
- **Sands support booklet for parents:** *Deciding about a post mortem: Information for parents.* This new booklet explains what a post mortem is and the possible benefits of having one. It also describes the choices parents can make so that they can decide what is right for them.

The post mortem package has been welcomed by a wide range of organisations, health professionals and others working with bereaved parents:

Baroness Diana Warwick, Chair of the Human Tissue Authority: “We are extremely pleased to have supported the important work of Sands by contributing to the development of their post mortem consent package. When a baby dies, it is an enormously distressing time for the family. It is important that the best possible information about post mortem examinations is offered to parents so that they can make an informed decision about whether it is right for them.”

Baroness Warwick continues: “The package will also help ensure that healthcare professionals who seek consent from parents can answer their questions and are sensitive to their needs. We encourage all hospitals involved in perinatal post-mortem examinations to consider adopting the Sands consent package.”

Professor Cathy Warwick, Chief Executive Officer, Royal College of Midwives: “The RCM is delighted with all the work that has gone into this invaluable resource for practitioners and is very pleased to support it.”

Dr Alan Fenton, Consultant Neonatologist: “This will be a huge step forward in achieving a consistent approach to bereaved parents around a highly sensitive issue, and a great help to the professionals who support them at this very difficult time.”

The post mortem consent package was developed in association with the Human Tissue Authority, and with funding support from the Department of Health.

The Sands post mortem consent form has been 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. 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 materials in the package - the guide for consent takers and the information booklet for parents - are relevant throughout the UK.

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

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Notes to editors:

Case studies available - Sands has a number of parents throughout the UK who are willing to share with the media their own personal experiences of the loss of their baby and post mortem.

For further information, please contact Sands press office:

Lisa Wardle – 0845 6520 459 or 07554 454 309

Katie Duff – 0845 6520 442 or 07554 454312

Lyn Peters – 01394 385 865

Key Information about Sands:

Sands, the stillbirth and neonatal death charity, was established by bereaved parents in 1978 and obtained charity status in 1981.

Sands core aims are to:

- Support anyone affected by the death of a baby;
- To work in partnership with health professionals to improve the quality of care and services offered to bereaved families; and
- To promote research and changes in practice that could help to reduce the loss of babies' lives

Sands is a national organisation, with around 100 regional support groups across the UK.

Helpline: 020 7436 5881

Office: 020 7436 7940

Web: www.uk-sands.org

E mail: info@uk-sands.org

References:

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