Learning Outcomes for Consent Taker Training

Seeking consent/authorisation for a hospital post mortem examination of a baby

Introduction

All consent takers should be trained and specifically approved to take consent for a post mortem examination and should have observed a post mortem examination, if possible that of a baby. (Human Tissue Authority’s Code of Practice 1: 54).

At present, there are no agreed training standards for seeking post mortem consent or authorisation, and the provision of training for consent takers is patchy. A recent study found that 26% of midwives and 13% of obstetricians had no training in taking consent, while 33% of midwives and 11% of obstetricians were dissatisfied with the training they had received (Heazell et al 2012).

Sands, the stillbirth and neonatal death charity, has produced these learning outcomes to help improve and standardise training for consent takers. They are based on the Sands Guide for consent takers: seeking consent/authorisation for the post mortem examination of a baby and have been developed in consultation with the Human Tissue Authority (HTA).

Further copies of this guide, and the other documents in the Sands Post mortem consent package, can be downloaded from the HTA’s website: www.hta.gov.uk/legislationpoliciesandcodesofpractice/modelconsentforms/thesandspostmortemconsentpackage.cfm

This list of learning outcomes includes all the skills and information, including local information, that consent takers should have before they are approved to seek consent. They cover:

- the law and legal requirements.
- taking consent for a hospital post mortem.
- what happens at a post mortem examination and the options available to parents.
- essential information about local arrangements for post mortems.
- communication skills.

It is not necessary or implied that all these topics should be covered in the same training session. They may, for example, be covered in different modules within a longer course, or in separate sessions on specific topics. Participants may already have had the necessary training on some of the broader topics, eg, communication skills and breaking bad news. What is important is that each consent taker has covered all the content.

There is a list of required and recommended reading at the end of this document.

Note: The terms “consent” and “coroner” are used in England, Wales and Northern Ireland, and “authorisation” and “procurator fiscal” in Scotland.
Learning Outcomes for Consent Taker Training

1. The law and legal requirements
Consent takers should know:
- the circumstances in which a death must be referred to the coroner/procurator fiscal.
- the consent that is required for a hospital post mortem.
- the consent that is required to use and store human tissue. Note: the law in Scotland differs slightly from that in England, Wales and Northern Ireland.
- who can give consent when a baby dies.
- how to assess mental competence in relation to informed consent.

2. Taking consent for a hospital post mortem
Consent takers should know:
- that, unless the death is being referred to the coroner, all parents whose baby has died should be offered the opportunity to discuss having a post mortem examination so that they can make an informed choice.
- that no assumptions should be made about who will and who will not consent to a post mortem on the basis of, for example, religion or ethnicity.
- that parents should never be given a post mortem consent/authorisation form without some preliminary discussion and written information.
- that the consent taker is responsible for giving parents the information they need to make a decision and for answering their questions.
- that the consent taker should, before he/she approaches the parents, be familiar with the form to be used and with any written information about post mortems given to the parents.
- that the consent taker should always tell parents, before the form is filled in, that they can change their minds, and should give them a clear time frame and the details of a named contact.
- that the consent taker should never leave parents to complete the form on their own unless they specifically request this.
- that the consent taker should offer the parents a copy of the consent form when it is completed and signed.
- the procedures that affect parents when a death is referred to the coroner/procurator fiscal.

3. What happens at a post mortem examination and the options available to parents
Consent takers should know:
- what is involved in a complete, a partial and an external post mortem as well as the potential benefits and disadvantages of each option in terms of information likely to be gained.
- the additional benefits of examining the placenta and that, although consent is not required for this under human tissue legislation, the HTA considers it good practice to seek consent.
- how tissue blocks and slides are prepared, why they are needed and what they look like.
- the potential benefits to parents of the hospital keeping tissue blocks and slides as part of the medical record.
- why it might be recommended that one or more organs is kept beyond the time when the baby’s body would normally be returned for the funeral and how to seek consent/authorisation for this.
4. Essential information about local arrangements for post mortems
Consent takers should know about local procedures around post mortems and how these affect the options available to parents. These include:
- whether the baby would be transported to another hospital for the post mortem and the arrangements for this, including how the baby would be transported and kept safe.
- how the baby’s body would be cared for and kept safe in the hospital mortuary.
- local policy on organ retention.
- what is likely to happen, including referrals etc, if the post mortem identifies a genetic disorder.
- when the baby’s body is likely to be returned for the funeral.
- the choices that parents have about a funeral for their baby.
- who will give parents the results of the post mortem and when and where this is likely to happen.

The document *Compiling local information for post mortem consent takers* in the *Sands Post mortem consent package* lists in more detail the local information that consent takers need: http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/modelconsentforms/thesandspostmortemconsentpackage.cfm.

5. Communication skills
Consent takers should understand:
- the shock, confusion and distress that newly bereaved parents are experiencing, and how this may impair their ability to listen, understand and make decisions.
- the importance of ensuring privacy and uninterrupted time to discuss post mortem consent.

Consent takers should be able to:
- communicate clearly and empathetically with the parents.
- outline the post mortem process and the different options sensitively and in language that the parents can understand.
- tailor the amount of information he/she gives according to the needs and wishes of the parents and the requirements of the consent/authorisation form.
- help the parents to reach decisions that they will not later regret.
Required Reading

- The Sands Guide for Consent Takers
- The Human Tissue Authority’s Codes of Practice 1, 3 and 5 www.hta.gov.uk
- The Sands booklet for parents: Deciding about a post mortem examination

Reference and Recommended Further Reading


www.uk-sands.org

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