

Post-Mortem Authorisation – Parent to Parent

Nicola Welsh¹, Kate George², Margaret J Evans³

1) SANDS-Lothians, 177 Colinton Road, Edinburgh EH14 1BZ, UK.

2) Kate George Design, Studio G13, Out of the Blue Drill Hall, 36-38 Dalmeny Street, Edinburgh, EH6 8RG, UK.

3) Corresponding Author - Department of Pathology, Royal Infirmary of Edinburgh, Little France Crescent, Edinburgh EH16 4SA, UK, Centre for Comparative Pathology, University of Edinburgh, Edinburgh, UK. Email: margaret.evans@nhslothian.scot.nhs.uk

BACKGROUND

Post-mortem (PM) and placental examination can provide vital information for care in the next pregnancy as well as allaying parental anxiety. Unanswered questions and doubts can lead to negative feelings and can complicate grief. A recent study showed that consent/authorisation to post-mortem was influenced by deprivation and ethnicity and raised questions as to the suitability of materials provided to parents when considering post-mortem.

OBJECTIVES

This study was designed to examine what parents want to know about the process and to involve them in provision of accessible materials which address their concerns. The use of simple language and short "sound bites" within an animation will enable informed decision making regardless of background or reading ability.

METHODS

Bereaved parents who engaged with SANDS-Lothians were asked if they would share their experiences of the autopsy process in order that parental concerns could be addressed in a video designed for parents considering autopsy. Participation was entirely voluntary.

The questions asked were:

- 1) List (briefly) 5 things you would have liked to have known about PM BEFORE making your decision?
- 2) Why you made the decision to have or not have a PM?
- 3) How you feel about your decision now?
- 4) Would you like the video to include some information about the PM process?

The information provided was reviewed and themes extracted. The animator designed a story board which was reviewed by parents and relevant "sound bites" added. The responses were used to create an animated 2–3 min video using a Q&A format to address the "real" issues identified by parents alongside an informative illustrated leaflet.

RESULTS

16 families, 18 babies and a total of 19 parents answered the questions while many others asked to be involved in reviewing the art work prior to finalising the video and leaflet. The main themes identified were consistent in all the responses received and related to: Why? When? Where and by Whom?

Families also needed to know that the body would be treated with dignity and respect, what might happen to the body between the autopsy and the funeral. Would keep-sakes be kept with the body? Could the baby be carried to the mortuary? How long to receive results and from whom? Many also felt they should be told about the likelihood of no cause being identified.

CONCLUSION

The responses from the parents were not as predicted by professionals involved in writing the video script. In view of this we worked closely with families to create the animation using real voices and real opinions.

This study demonstrates the need to listen to parents and be guided by them when creating resources; there is a general need for improved communication between all working in this area including the ability to give parents time to reflect on their loss and on concerns they may have before discussing post-mortem consent in detail.

Keywords: post-mortem, animation, informed consent, authorisation, parents

