

# APPENDIX N

## INFORMATION FOR HEALTH PROFESSIONALS SEEKING CONSENT – OBTAINING PARENTAL CONSENT FOR THE AUTOPSY OF A BABY

### OBTAINING PARENTAL CONSENT FOR THE AUTOPSY OF A BABY

#### IMPORTANT INFORMATION FOR THE HEALTH PROFESSIONAL SEEKING CONSENT

The death of a baby is a devastating time for parents and their family. In many situations the death is unexpected and the parent is confronted with both the shock of losing their baby, as well as the overwhelming emotions that follow. Research has indicated the importance of compassionate care and provision of information in the time surrounding the death of a baby\*. One aspect of this is approaching bereaved parents to discuss the autopsy. The purpose of this pamphlet is to provide guidance to the health care professional in discussing stillbirth and neonatal autopsy with bereaved parents.

Each hospital should have its own policy and procedures regarding obtaining autopsy consent. This policy should initially be consulted.

#### Why is it important to seek parental permission for post-mortem examinations?

There are a number of common misunderstandings within the community regarding autopsy. Parents may be unwilling to give consent, due to concerns about organ retention or that they will not be able to see their baby following the examination.

Provision of information regarding the reasons why autopsies are performed may make it easier for parents to consent to its request.

#### When is the best time to ask?

The best time to request parental consent for a autopsy varies significantly from parent to parent and may also be dependent upon the circumstances surrounding the baby's death. For instance, if a baby dies in utero, the request may be made once the parent has processed the information that their baby has died and prior to delivery. In this instance, some parents may be too distressed immediately following the delivery, while others may not consent after a significant period of time due to protective instincts toward their baby. It is also commonplace for women to not comprehend that their unborn baby has really died until their baby is delivered, so mentioning autopsy prior to the birth of the baby could be very difficult in this circumstance.

#### Who should ask?

The person who may be best at judging the most suitable time to request consent is the health professional who knows the parents best. If this is not an option, consultation should be sought from a professional experienced in requesting autopsy.

Due to the sensitive nature of the issue, the person most appropriate to approach the parents would be the most senior doctor, consultant obstetrician or paediatrician, or the health professional that has an established relationship with the parents. In all cases, the health professional must be familiar with the process of seeking parental consent for post-mortem examination, and be competent in answering all of the parents'

questions relating to the procedure. Excellent interpersonal communication skills are essential to ensure that the request is delivered in a sensitive and informative manner.

#### Where should the discussion be held?

The most appropriate environment is in a quiet, private room away from other patients, relatives and hospital staff. It is not appropriate to request permission in a corridor, shared room or public waiting room.

#### How do I ask parents for permission for an autopsy?

The treating consultant should explain to the parents the clinical indications for conducting an autopsy. It is appropriate for the consultant to recommend that an autopsy be performed.

In seeking consent, the health professional should approach the discussion with honesty, integrity and respect.

Do not use terms such as fetus, products of conception or termination, or any words that may take away the humanity or individuality of the baby. Always try to use the baby's name, if culturally appropriate as this helps to validate the importance of the baby to the parents, as well as the significance of the loss.

Parents may require some time to make their decision, during which they may formulate several questions. It is important that these questions are accurately addressed. Parents may prefer that discussions about

autopsy are not conducted in the presence of their baby. Be aware of any cultural or religious beliefs concerning death and dying and show sensitivity to these beliefs when discussing autopsy with parents. On the other hand, do not assume to know what is required of religions with which you are unfamiliar. If you are uncertain, or do not know, it is reasonable to ask the parents what is required.

Be prepared to give parents written information on the autopsy procedure, but be aware of how much detail the parents wish to know before presenting this information. Few people are familiar with autopsy procedures. It is important to know that parents may require information several times due to deficits in information processing as the result of shock and grief.

### Information you need to know

- Know where the baby will be taken for the autopsy and when s/he will be returned and available to the parents. Inform them that they will be able to see and hold their baby afterwards if they wish.
- Be able to give advice regarding the presentation of their baby after autopsy, for example, where the incisions will be made, their approximate size and that they will be stitched as in other surgical procedures. Parents should also be told that the baby's body may be more fragile than prior to the autopsy.
- Explain to the parents that the baby will still be returned to them for burial. You will need to explain that if an organ is to be retained, the parents can either delay the funeral, have a separate burial or return of cremated organs at a later time.
- Know, if possible, when the results of the autopsy will be available and if appropriate, make an appointment to see the parents to discuss these results. Give parents the contact details of who will

be able to keep them advised about the progress of the report.

The amount of information you give to parents will depend on their need for details. Prompts may be helpful as many parents feel that their questions may be too simple or trivial.

Parents should be provided with written information regarding post-mortem examinations to allow frequent reference. Please refer to the pamphlet: Explaining Autopsy: Information for Parents When Your Baby Has Died"

Before consenting, some parents may like the opportunity to discuss their feelings with other bereaved parents. Please refer to the PSANZ website on <http://www.psanz.com.au> for a list of relevant support groups for each state.

### Discussing results

It is important to explain to parents that results may not be available for several weeks or months and that provisional results may be available sooner. In some cases, final results may not be available for up to 6 months or longer. This will help to reduce anxiety in the parent as they wait for the final report.

Ensure that when the results are discussed with parents, they are fully explained without the use of medical terminology. Allow time to answer all questions and concerns about the results. Do not edit or withhold information from parents.

### Summary – Do's and Don'ts

- allow plenty of time with parents
- always be honest
- use the baby's name

- not use terms such as fetus, products of conception, termination, or any words that take away the individuality of the baby
- use a quiet, private place to conduct discussions with parents
- introduce details at the individual's pace and use language that parents understand
- provide written material
  
- make a note of what you say and of what the parents say
- give parents time to make their decision
- treat parents with respect.
- Do not get defensive. Parents may be looking to blame doctors and they may be feeling hostile and angry. These are real emotions that may help the bereaved parent to maintain a sense of control in an uncontrollable situation. These emotions must be acknowledged by you in an understanding and supportive manner.

### Who Can Parents Contact if They Wish to Discuss Their Feelings with Other Bereaved Parents?

Provide SANDS and Red Nose information – whichever is relevant in each state.

\*See PSANZ Perinatal Mortality Audit Guideline, Section 3 for list of references.

*Acknowledgement:* This brochure has been adapted from the original version written by Medical Students of the Graduate Medical Course, University of Queensland in conjunction with bereaved parents of the Stillbirth And Neonatal Death Support Group (Qld) Inc. including Miscarriage Support in May 1999.