



Section 3 of 7 – Psychological and Social Aspects of Perinatal Bereavement

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SECTION 3 PSYCHOLOGICAL AND SOCIAL ASPECTS OF PERINATAL BEREAVEMENT

3.1 Introduction

Health professionals are typically involved with bereaved parents during and immediately following the death of their baby. Despite this, the training of health professionals in the care of parents following the death of a child has been reported to be one of the most neglected areas of education^(1, 2). In the absence of such training, professional, cultural and societal assumptions of how patients should respond to perinatal loss influence the quality of emotional care provided to patients by health professionals. Health professionals may themselves find it difficult to provide sympathetic and compassionate care due to a lack of knowledge and understanding of how best to approach this difficult situation.

Research has suggested that the role of practitioners in the handling of death and their interaction with the bereaved person following a loved one's death influences the intensity of grief^(1, 2). One study found that grief levels in bereaved persons were significantly reduced when the practitioners involved them in medical decisions and decisions relating to the deceased person's care⁽³⁾. It is proposed that skilled, sensitive and caring treatment in the time surrounding pregnancy loss positively impacts on the grief experience of bereaved parents^(1, 3). Disempowerment, an absence of acknowledgement and validation for their physical and emotional experience and lack of information^(1, 3, 4) and insensitive and unsympathetic care⁽¹⁾ may result in intense feelings of guilt, misunderstanding and rumination in the bereaved parent^(1, 4).

A number of studies have examined the factors considered to be important to bereaved parents following the death of their child, as well as aspects of care that they considered to be lacking⁽¹⁻⁶⁾. These findings implicate the importance of validation and acknowledgement of the physical and emotional aspects of their experience; empowerment and safety; collaborative decision-making; the sharing of knowledge; creation of memories; and sensitive care. One study⁽⁴⁾ found that parents reported higher levels of sensitive care when the clinician associated the death with a similar event in his or her own life experience rather than an experience in their training. Further, it is important that clinicians accept the range of responses given by bereaved parents and that they do not project their own values or expectations upon those in their care. The Cochrane systematic review on the topic of support concluded that there is insufficient information available from randomised trials to indicate whether there is or is not a benefit from interventions which aim to provide psychological support or counselling for mothers, fathers or families after perinatal death and recommended that methodologically rigorous trials are undertaken⁽²⁷⁾.

Based on these findings, the following information is provided as a guide to assist clinicians in providing positive treatment for the bereaved parents and their baby.

A subgroup of the working party (Kylie Lynch, Liz Davis, Sonia Herbert, Ros Richardson, Dell Horey and Vicki Flenady) worked collaboratively in the development of the first edition of this section of the guideline. The review and minor updating of this section for this second edition was undertaken by Liz Davis, Ros Richardson and Vicki Flenady.

3.2 Summary of key recommendations

Respect

For baby	Deceased baby to be treated with same respect as live baby
For parents	Parents need to feel supported and in control; death validated
Cultural/religious practices	Different approaches to death and rituals respected

Provision of Information

Timing of information	Allow plenty of time to discuss issues at most appropriate time
Delivery of information	Clear, honest and sensitive. Repeat important information. Ensure both parents are present.
Mode of information	Fact sheet/written information given for frequent reference
Withdrawal of support	Parents given prognostic information to reach decision
Terminology	Parent friendly language. Do not use terms such as fetus
Post-mortem examination	Verbal and written information given. Allow time for discussion Ensure both parents present when discussing autopsy – the parents may also be assisted by having a support person (family, friend) present

Birth Options

Timing	Ascertain appropriate time to discuss birth options following determination of a fetal death in utero or abnormalities
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Mode of delivery	Benefits of birthing options given
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Time

Parents are given time to make decisions
Inform parents of how much time can be spent with baby

Hospital Stay

Environment	Parents are given the option of a private room in surgical, maternity or gynaecological ward Universal symbol placed outside room to alert all staff of death
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Creating Memories

Spending time with baby	No hurry to leave baby or hospital. Option to take baby home
Parenting baby	Inform parents that they can hold, undress, bath baby
Mementos	Helpful for long-term grief outcome. See <i>Section 3.2.6</i>
Baptism/blessing	Inform parents that this can be arranged through the hospital

Special Circumstances

Multiple pregnancies	Special care is required in the circumstance where some infants in a multiple pregnancy survive.
Maternal illness	Consideration given regarding access to baby/memory creation
Previous perinatal/child death	Consider impact of previous death/s on emotional response to and coping with current death

Aftercare

Maternal changes	Advise on milk production and methods to manage supply
Support services for parents	Written information given regarding available support services
Support services for children	Written information provided for children's support services
Grief	Inform parents of expectations of grief journey
Follow up/Appropriate referral	Expectations for 6 week check up – other babies present

Funeral Arrangements

Parents given choice of funeral directors
No urgency to organise funeral
Continued access to baby if desired

Health Care Professionals

Education Specific training in support skills given to relevant staff
Access to support Debriefing/support services available to staff working with perinatal death

3.2.1 Respect

For baby

The baby should be respected, just as if a live baby. This includes the way in which the baby is handled. Use of the baby's name (where applicable and culturally appropriate) is recommended. This suggests to the parents that you recognise the baby's individuality and helps to validate their loss. Parents need to know that their baby will be cared for with dignity and respect at all times.

For parents

Parents should be supported to enable them to feel that they have some control. They should be provided with enough support to enable them to reach their own decisions regarding their care and the care of their baby. The provision of care needs to be responsive to their individual needs and feelings.

The depth of their loss needs to be recognised and validated. The death of a baby through stillbirth and neonatal death can be isolating for parents due to the assumption that the death is less significant than that of an older child⁽⁷⁾. Many parents also face a shattering of worldview, as the death of a baby violates the natural order of life, where it is expected that the old will die before the young⁽⁷⁻¹¹⁾.

For cultural and religious practices

People of different cultures approach death in different ways. This belief system may vary both across and within their culture. They may also have rituals that they traditionally perform following the death of a loved one. These rituals should be respected in instances where they comply with state regulations. Sufficient information is also provided to enable the ritual to be carried out. It is important for practitioners to gain a general working knowledge of cultural practices to avoid offending the bereaved parent. For example, the stillborn baby of a Muslim woman may be bathed by a same sex relative; questioning and eye contact may be considered to be offensive by an Aboriginal woman.

3.2.2 Provision of information

Timing of information

Health care professionals need to be sensitive to the needs of bereaved parents and aware of appropriate times to deliver information. Parents should be assisted to understand and appreciate the issues on their own terms and understand the important aspects of diagnosis, treatment, consequences and outcome. Provision of information should allow parents the time for consideration. Allow time for questions and allow time for silent grieving also. It is therefore necessary to allow adequate time to spend with the bereaved parents. Be flexible and repeat the information as required. Ensure that both parents are present when information is to be given. This is particularly relevant when an IUFD has been diagnosed. If the mother is on her own, her partner or other support person should be contacted. It should be recommended that she not drive home on her own.

Delivery of information

Communication needs to be clear and honest and delivered in a sensitive manner. There may be a requirement to provide parents with the same information many times over due to information processing deficits caused by shock and/or grief. It is important to ensure that both parents process the information that is given and that both achieve the same understanding of the information to enable the parents to make accurate and informed decisions. If the baby has been named and it is culturally appropriate to do so, always use the baby's name during discussions.

Information should be delivered in a quiet, private room, away from other patients, relatives and hospital staff.

Parents understanding of the issues should be actively assessed by reflective listening while communicating with parents. Where the situation requires (e.g. Giving of consent for intervention), it is important that decision-making is based on a fully informed appreciation of the issues. Take the opportunity to ensure that parents' understanding of the situation is accurate in terms of the facts and up to date in terms of the clinical progress. Many parents will be more in tune to the issues than staff anticipate; however it is important to constantly assess that parents understanding is based on correct information and not on false hopes. Where possible, ask specific questions to confirm parents understand, particularly when discussing possible new interventions or changes to treatment plans. Parents may appear to understand the information being given but may in fact not be able to recall the conversation at a later time.

Competent interpreters should be used in cases where the parents are not fluent in English.

The National Health and Medical Research Council has recently produced guidelines to assist clinicians to communicate more effectively and provide information to patients^(12, 13) (*Please refer to these documents for full details.*)

Mode of information

Parents generally have difficulty absorbing and retaining information during and following the death of their baby. It is therefore useful to reinforce verbally delivered information with a fact sheet or written information about issues relevant to the parents, their baby and their loss.

Offer parents Stillbirth And Neonatal Death Support (SANDS), SIDS and Kids and/or Support After Fetal Diagnosis of Abnormality (SADFA) support group brochures – whichever is applicable to their circumstances.

Withdrawal of support (14, 15)

Parents need to be provided with all information regarding their baby's condition and prognosis to enable them to reach the decision of withdrawal of support themselves or in conjunction with the Neonatologist. Parental decision to withdraw support on the grounds of compassionate care reduces the risk of parents blaming practitioners for their baby's death. It is natural for parents to want to protect their baby and the withdrawal of support may be considered to contravene this innate quality. To assist parents thinking about withdrawal of care from their baby, parents need to be provided with full and honest information regarding their baby's prognosis. This information needs to be delivered compassionately and sensitively and preferably from one Neonatologist in order to avoid discrepancies in information and/or prognosis, although parents should be offered the opportunity to seek a second opinion. Where possible, concrete evidence regarding the poor prognosis should be given. It is essential that all aspects of the baby's condition and prognosis be discussed to avoid the perception that a different agenda exists for the recommendation of withdrawal of support. Encourage parents to speak to others (family, friends, and social worker) about the decision to withdraw support. Speaking to others may allow them to express their fears and anxieties and assist them to make an informed decision.

Staff caring for the baby should provide parents with the opportunity to hold their baby prior to death. Parents are generally guided by staff during this time and all efforts should be made to make the experience as compassionate, sensitive and meaningful as it can possibly be. Privacy is essential at this time and can be provided by offering a private room (where possible) or screen (if in Neonatal Intensive Care Unit). Staff should be guided at these times by the principles of compassionate, supportive and empathic care. Respect for the baby and his/her life and respect for the intensity of parental grief are crucial.

Parents need to be informed that it is often difficult to predict how soon a baby will die following the withdrawal of support. Many parents may expect this to be a quick process and may become distressed when their baby continues to live for some time following the withdrawal of support. This may create a situation where some parents question their decision and may feel anger and uncertainty with the advice and recommendations of staff. It can be helpful for parents and staff to agree on how the baby will be cared for after the withdrawal of support until the baby dies. However, some babies may die very quickly after support has been withdrawn – it may be necessary to ensure parents are on hand at the start of the process.

Terminology

Parent friendly language should be used when discussing issues pertaining to the death of their baby. Where possible, establish the parents' level of understanding. Some parents may have spent days or weeks with their baby and have a detailed and sophisticated understanding of the problems and the treatment plan. However, in many cases, there will be no antenatal diagnosis and post-natal problems may occur very

rapidly, leaving very little time to provide detailed technical examinations of what is going on. Medical terminology should be avoided as many parents have minimal understanding of these terms and have a limited capacity to understand during this traumatic time.

It is imperative that health care practitioners avoid the use of terms such as fetus and products of conception. These terms dehumanise the baby and take away his or her individuality. The use of the baby's name (where culturally appropriate) in place of any term helps to validate the importance of the baby and the depth of loss for the parent. Health care professionals need to be clear in their communication with parents when discussing procedures around labour and delivery.

Autopsy

Parents should be provided with verbal and written communication regarding their options for post-mortem examination. Sufficient time should be allocated to explain the options available and to answer any questions that the parents may have. Parents should be informed that a decision is not required immediately and have access to information and support. A follow up appointment may be required if the parents are unable to decide during the initial meeting. It may be beneficial to the parents to have a support person present when the discussion is being held. It is important that the person requesting permission understands the process of autopsy and be able to answer, within their knowledge, questions the parents will have. The health care professional who is to speak to the parents should already have developed a rapport or relationship with them. Options for autopsy, such as a partial autopsy, need to be discussed.

Parents should be given the opportunity, where possible, to meet with the pathologist who will perform the examination. Assurance that their baby will be treated with respect needs to be given. Parents need to be given the option to see and hold their baby after the autopsy has been performed, either in the hospital or at the funeral home. The pathologist will need to understand that parents may see and hold their baby after the autopsy. It is important that the person taking their baby to the autopsy be known to the parents. The discussion regarding autopsy should be in a quiet, private place away from others. It is not appropriate to discuss autopsy in a corridor, shared room or other public place.

Parents need to know that it may take several months for the results to become available to them. It is also important to inform the parents that there is a chance that nothing adverse will be discovered.

(Please see Section 3; Appendix 1 Information for parents when your baby has died, and Section 3, Appendix 2 Information for the health professional seeking consent.)

3.2.3 Birth options

Timing

In the event of a diagnosis of fetal death in utero or fetal abnormalities that are incompatible with life, parents are faced with both the reality that their baby has died (or will die) as well as the need to deliver the baby. Parents should be informed of factors relating to delivery, e.g. when to deliver, how to deliver, and the impact that waiting to deliver will have on accuracy of post-mortem examination results, etc. Parents may be experiencing a range of emotions such as shock, disbelief and grief, and have difficulty processing information. The timing of delivery of information is important to provide parents with the opportunity to make appropriate decisions relating to the birth of their baby. The health care professional who is most closely involved with the parents would be the most appropriate person to determine the best time to discuss these issues, although parents should be offered an alternative person with whom to discuss their options. In the event that no particular person has been involved in their care, the practitioner who is most experienced in discussing these issues should approach the matter. Amniocentesis before delivery, if appropriate should be discussed with parents – the health care professional working with the parents should have knowledge of current practices.

Mode of delivery

Where possible, parents should be offered a choice in birthing options. Many mothers find the concept of delivering their stillborn baby naturally to be overwhelming. However, some mothers report satisfaction and a sense of accomplishment with natural delivery following the determination of a fetal death in utero⁽¹⁶⁾.

In the event of interruption of pregnancy due to abnormalities, the benefits of delivering naturally or by caesarean versus dilatation and curettage should be explained. Seeing and holding the baby and creating memories is an important part of the grief process for many, but not all, women. Women and their partners need to be informed that if their baby is delivered (removed) by a dilatation and curettage procedure, their baby's body will not remain intact.

In all circumstances where options are available, natural delivery vs. delivery by caesarean section and the benefits of each mode should be explained to the parents. For example, a baby may be born alive if delivered by caesarean and may not survive a natural birth. Consequences of caesarean delivery on future pregnancies/births should be discussed.

Ensure that the parents are fully informed before commencing any procedure. Where possible, offer parents the option of returning home prior to induction/delivery. Going home before delivery can give parents time to consider the information they have received and gather their support people around them. They will also have time to think about memory creation – camera, video camera etc. It is important to remember that it may not always be appropriate to ask the father to return home on his own immediately after a fetal death has been diagnosed. Parent safety is paramount. It may be helpful for the mother and father to stay together while a friend or family member brings necessary items to the hospital.

The primary caregiver is favoured to present the parents with available options as rapport and trust is already established. In the event that this is not possible, a person experienced in perinatal bereavement would be appropriate.

3.2.4 Time

Parents need to be given time to make decisions. Where fetal death in utero or fetal abnormalities have been determined, parents should be given a choice between remaining in hospital and returning home prior to induction. Information needs to be reinforced or in written form, if possible, to enable parents to prepare, discuss and decide between options⁽¹⁶⁾.

Practitioners should allow ample time to deliver information about the hospital stay, creating memories and consent for an autopsy and discuss issues and concerns, which may be raised repetitively.

3.2.5 Hospital stay

Environment

For some bereaved parents, it can be very distressing to return to or remain in the maternity ward. The sound of crying babies may add to their distress. Other parents may find it more upsetting if they are moved to the surgical or gynaecological ward and interpret this as meaning that they are no longer considered to be parents. It is therefore important to ask the parents if they would prefer a room in the maternity or surgical ward while they remain in hospital. Time with their baby should be available and they should be informed that there is no urgency to leave the hospital. It is important that clinicians do not impose their own preferences on parents and that they understand that not all parents want to hold or see their baby at this time. In these circumstances it is important that mementoes such as photographs are collected (see below).

Bereaved parents should be provided with a private room, away from the busiest part of the ward and a symbol placed on door to alert all staff to the situation. This needs to be a universal symbol with which all hospital staff is familiar, to help to ensure the continuity of sensitive care.

Continuity of care is recommended. A staff member should be available at all times to collect or return the baby at the parent's request.

Referral to a social worker must be made to provide support, counselling and information pertaining to support groups and funeral options. If it is established that the baby has a congenital abnormality or a genetic condition, a Genetic Counsellor, if available, can assist with bereavement care, provision of information and support.

3.2.6 Creating memories

Spending time with baby

Validating the death of the baby assists in facilitating a healthy grieving process and is enhanced by the encouragement of the creation of memories^(5, 15, 17, 18). Providing suitable clothing, blankets, cots and baskets and seeing, holding and naming their baby assists the parents in creating memories, which may aid in the grief process.^(1, 7, 15)

Parents may initially be reluctant or afraid to see their baby. While some research in the area of parental bereavement recommends encouraging parents to see and/or hold their baby⁽¹⁶⁾, others do not⁽¹⁹⁾. Therefore, it is important that the parents be encouraged to explore what is the best option for them in regard to seeing and holding their baby and their wishes respected. This is of particular importance when caring for parents of

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different cultural backgrounds. Parents may need guidance from the doctor or midwife in how to approach their baby⁽¹⁶⁾. Parents will often take their cues from the staff caring for them and their baby and will sense if a staff member is not comfortable caring for a baby who has died. Some mothers may like the baby delivered onto their chest so they experience the warmth of their baby.

Parents choosing to spend time with their baby should be informed about the length of time that they are able to spend with their baby. It is important to inform them that there is no urgency to arrange a funeral or leave their baby. Parents need to be informed of the option of placing the baby in the hospital morgue from time to time to preserve the baby's body.

Options need to be offered regarding staying at the hospital versus taking the baby home. Factors relating to climate need to be discussed, as time spent with baby in the home may be limited in hotter climates.

It is important that parents are prepared for the appearance of the baby, particularly when the baby is extremely premature or has a congenital disability^(15, 18). Providing a photograph or describing the baby's appearance can be helpful for the family. In circumstances where abnormalities are present, parents may prefer that their baby is presented in such a way that the abnormalities are less evident (for example, covered with blanket, bonnet or other clothes).

Parenting baby

Parents should be provided with the opportunity to bath their baby if they so desire. They should be informed that it is quite acceptable to hold and undress their baby. Options may need to be offered several times, as parents may not initially process the information. It can be helpful if staff offer to assist the family. Siblings may also wish to be involved in this care.

Parents should be informed of what to expect when the baby has abnormalities or is extremely premature. Staff should have this knowledge so they can better inform parents.

Inform parents of the option to provide clothes from home for their baby if they so wish.

Mementos

Although some parents may be reluctant to see their baby, there are a number of things that should automatically occur following the death of a baby. These include the compilation of memories that may be kept until the parents are ready to accept them. For some, it may be culturally appropriate to explain and obtain permission for procedures, such as taking photographs.

Parents may take days, months or years to decide that they would like these mementos; therefore no time provision should be made regarding storage. Some families may choose to never receive these items.

As a minimum, items included should be:

- hand and footprints
- ID bracelet
- measuring tape
- cot card
- digital photographs
- lock of hair (where possible and only after permission of the parents has been given)

Suggestions to parents for the creation of memories may include:

- photographs – of baby and with family
 - taken professionally – if a death is one of a multiple pregnancy, a photo of all the babies together.
 - without clothes
 - abnormalities – special attention given
 - photos during birth
 - photos on disc
 - video taping of the birth and afterwards
- hand and foot moulds
- blanket used to wrap baby
- clothes worn by baby
- Baptism clothes and service notes

Baptism/Blessing

Parents should be informed that this can be arranged with the hospital chaplain or a religious representative of their choice. In the event of stillbirth, parents should be informed that the service would be a 'Baptism of

Desire' as opposed to a traditional Baptism. Some families may choose to baptise or name their baby themselves, or have a relative or friend do this for them.

Where a baby is in the Intensive Care Nursery, parents should be given the option of a baptism prior to their baby's death. Parents may be reluctant to consider this option as they may feel that permitting a baptism is giving up hope that their baby might survive. It is important to inform the parents that a formal ceremony can take place at a later time.

3.2.7 Special circumstances

Multiple pregnancies

Parents of twins, triplets or quads may experience conflicting emotions when one or more of their babies die and one or more survive. Common emotions may include:

- guilt – relating to the amount of time spent with the deceased baby/ies, or for not devoting enough time to the surviving baby/ies because they are grieving;
- blame – of self or others; and
- grief – for deceased baby/ies while trying to bond with live baby/ies.

Parents may respond to the death of one or more of their babies by withdrawing from their surviving baby/ies through fear of them also dying. They may also feel torn between their surviving and deceased babies. It is important for additional support and information to be provided during this time. Parents may benefit from referral to support groups such as SANDS and SIDS and Kids for support and discussion with parents who have experienced similar losses.

Information should be provided to allow parents to make decisions such as:

- funeral arrangements – delaying funeral until the surviving baby/ies condition/s is/are determined; and
- possible benefits of autopsy for the surviving child/ren.

Maternal illness

Provisions should be made in the event that the mother is unwell following the birth (e.g. septicemia, admission to Intensive Care Unit, located in another hospital). Where possible, efforts should be made to provide an opportunity for access to baby during and/or after maternal recovery.

In the event of perinatal death, the baby should remain in the hospital (if possible) until the mother recovers. If the mother's illness is expected to exceed the time that the baby is able to be kept at the hospital, staff should recommend to fathers/family members the importance of creating as many memories as possible. Staff may discuss with the father or relevant family member the option of embalming the baby if it is expected that the maternal illness will be for a considerable time. This provides the mother with the opportunity to spend time with the baby following her recovery. Taking photos or video taping the baby with family members may be beneficial to the mother.

If the baby is going to be kept for some time, care needs to be taken with the placement of the baby so that unnecessary deterioration does not occur.

Mothers who have experienced prenatal illness or disease may feel intense guilt following the death of their baby. This may be a perception only as the baby may not have died as a result of maternal factors. This issue may need to be addressed by the staff member/s caring for the mother and detailed explanation given regarding the cause of death.

Previous perinatal/child death

Parental response to the death of their baby may be intensified by a previous perinatal or child death. Parents may experience a reliving of the previous death, which may significantly impede on their ability to effectively cope with the subsequent death. Other parents may have clear ideas regarding the way in which they chose to manage the death of their baby due to their experience. This may include the creation of memories and the way in which they chose to parent their baby. It is important for the practitioner to provide appropriate support and information and to be guided by the response of the parent.

3.2.8 Aftercare

Maternal changes

Many mothers are not aware that their milk will still come in. Mothers should be informed of this. This experience alone can be both physically and emotionally painful. The option of a consultation with a lactation

consultant should be offered to discuss ways to manage and decrease milk production. Mothers also need to know about other post-pregnancy changes such as bleeding. They need to be informed that an early check up with their General Practitioner (GP) or obstetrician is required at 6 weeks post birth and suggestions regarding timing of the appointment should be discussed (e.g. Other pregnant women in waiting room – suggest making last appointment for the day). When the appointment is made, suggest that the receptionist be told about the death of the baby so an appropriate appointment can be made.

Support services for parents and children

Written information provided regarding support services available for parents and children can be found on the PSANZ website: www.psanz.org.au, under Perinatal Mortality Group.

While high quality research on the effects of support interventions which aim to provide psychological support or counselling for mothers, fathers or families is lacking⁽²⁷⁾, from the currently available research and from understanding and experience in grief and loss be the developers of this guideline, the following information and advice is provided to assist clinicians in providing appropriate care for parents after a perinatal death.

Grief

Bereaved mothers have been found to experience more intense grief reactions and depression than do bereaved spouses, siblings or adult children⁽²⁰⁾. Parental grief is often protracted and intense^(9, 10, 21, 22). What is normal in parental bereavement often would seem exaggerated or abnormal in other types of bereavement⁽²²⁾.

Bereaved parents respond to grief in a number of ways. Denying the importance of their loss leaves bereaved parents vulnerable to delayed or complicated grief reactions^(22, 23). For many, the death of their baby is their first experience with the loss of a loved one. It may be useful to inform parents that their grief is a normal response to death.

Numerous studies have found that gender differences exist in the grieving styles of mothers and fathers following the death of an infant^(3, 6, 9, 10, 21, 23-25). Common trends in grief behaviours of women include:

- more likely than fathers to cry with others
- more likely to openly seek support both within and outside of the home
- a desire to speak tirelessly about the baby
- a constant preoccupation with their loss

Common trends in grief behaviours of men include:

- a preference to seek solitude
- reports of grief being a private concern
- disappointment in questions relating to their loss generally focussing upon how the mother is coping
- avoiding discussing the baby in social or work environments

Parent's long term adjustment may improve if given expectations of the grief journey and the different responses that may arise for mothers, fathers and children^(11, 25).

Medical care is generally centred on the mother in the time surrounding perinatal loss. This may apply also to emotional care. A father's grief is often overlooked during this time. It may be important for the bereaved father's long-term adjustment that his grief is also acknowledged⁽²³⁾.

Follow up

A follow-up appointment with the senior obstetrician and/or Neonatologist is required within two months of the baby's death⁽¹⁵⁾. This appointment should be made in rooms away from the hospital where possible, or the first or last appointment for the day should be offered, so that the parents can avoid coming into contact with newborn babies or pregnant women. During this appointment it can be helpful for parents to talk over their experience with the doctor. They may find it valuable to prepare questions in advance.

All efforts should be made to enquire after the parents' welfare and to explain the circumstances surrounding their baby's death. Autopsy results (if available) are given. If autopsy results are not yet available, an anticipated date that they will be available should be provided as well as information regarding how the family will be informed. Implications for future pregnancies, if known, should be discussed.

Where possible and if culturally appropriate, use baby's name. Do not use impersonal terms such as fetus when referring to the baby, and avoid unnecessary medical terminology, except where this is necessary to accurately describe the situation.

Appropriate referral

Referral to relevant health care professionals for different treatment options should be offered. For example, genetic counsellor (if needed), obstetrician (to discuss future birth options), support groups such as SANDS (Stillbirth And Neonatal Death Support Group), SIDS and Kids, and SAFDA (Support After Fetal Diagnosis of Abnormality), social worker, pastoral care worker.

To date, no evidence from randomised control trials exists to suggest greater advantages of specialised psychological support or counselling over sensitive routine perinatal care following perinatal loss^(26,27). It may therefore be necessary to offer the parents an external referral to an appropriate treating professional, e.g. psychiatrist, psychologist, bereavement counsellor, if the practitioner is of the opinion that this intervention is required.

3.2.9 Funeral arrangements

Parents should be informed of their options in relation to funeral arrangements. It is a legislative requirement to arrange a funeral for a baby whose gestation is 20 weeks or greater. Parents should be informed of this, as they may not be aware of this requirement.

It is useful to provide the parents with written information regarding funeral directors and to include several options. Funeral companies vary widely in the range of services they provide. Some funeral homes offer free or reduced funeral costs to families whose baby has been stillborn or died in the newborn period. There is also the availability of government funded funerals in some circumstances. Information regarding this and other benefits is available from Centrelink.

The funeral director should advise parents that they have access to their baby while their baby is in the funeral home. The options of bathing and dressing their baby, placing the baby in the coffin or spending time together before the funeral are also often available. It should be reinforced that there is no urgency for the funeral.

3.2.10 Health care professionals

Staff working with bereaved parents should be provided with an opportunity to develop their knowledge and understanding of perinatal loss, together with development of skills in working in this area^{(1),(9)}. Encouragement and support of medical and midwifery staff in their professional development, specifically with regard to bereavement care, is vital to ensure provision of skilled assistance to women and their partners under their care.

Imaging staff may also benefit from professional development in bereavement care. They are often the first practitioners to discover abnormalities that are incompatible with life or that a baby has died in utero. This training should focus on the role of non-verbal communication in perinatal loss. It is also important to recognise the importance of "being" with the bereaved family and providing gentle, quiet reassurance and support without the need to "do" or say a lot.

Sonographers and other imaging staff who provide services to pregnant women should develop policies and procedures for staff to follow in the event of a diagnosis of fetal abnormality, FDIU or pregnancy loss. These policies and procedures should focus on responsive care for all front of house staff and imaging staff caring for women who are shocked and distressed about the findings on their ultrasound scan. Policies and procedures should incorporate care for parents after the delivery of bad news, ensuring parents are not sent home in a state of shock.

Access to support

Staff working with bereaved parents should have access to support to avoid burnout. Check hospital policy regarding Employee Assistance Programs or provide access to appropriate professional (e.g. social worker, midwife experienced in perinatal loss and staff debriefing).

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Section 3; Appendix 2 Information for parents about autopsy

EXPLAINING AUTOPSY

INFORMATION FOR PARENTS WHEN YOUR BABY HAS DIED

The death of a baby is devastating. It is a time when you may have to consider issues such as a post-mortem examination for your baby. The following information is provided to assist parents in making a decision about a post-mortem examination.

What is an autopsy?

An autopsy examination is performed after death to find out as much as possible about why your baby died. The examination is performed by a pathologist, a medical practitioner who specialises in this field.

Why consent to an autopsy?

There are a number of reasons why you may decide to consent to an autopsy. These may depend on the age of your baby and the circumstances of his or her death. While it is difficult at such a time to think about future pregnancies, an autopsy may help in the management of a future pregnancy.

Autopsy may help to tell us:

- Cause of death or what to exclude as cause of death
- Gestational age
- Time of death
- Impact of genetic or physical problems
- Whether obstetric and/or paediatric care was appropriate
- Information important to the health of other children

Your doctor may suggest other reasons as to why you might consent to a post-mortem examination of your baby's body.

Where will the examination occur?

The autopsy will be performed at a centre specialising in perinatal autopsies. This may be within the hospital where your baby was born.

What happens during an autopsy?

There are several types of autopsy, all of which require your consent. The following provides a brief description of each examination:

1. Full autopsy – this allows the pathologist to look at possible external and internal anomalies, structural defects and organ growth. A surgical cut (or incision) is made from the shoulder blade to just below the naval, which allows an examination of chest and abdominal organs. A small incision is also made at the back of the head to examine the brain. The face, hands and limbs are never cut. Like all surgical procedures all incisions are stitched up and are normally not visible once your baby is dressed. Pathologists adhere to standards set by the
2. Limited autopsy – this is an examination that you have placed restrictions upon. For example, you may decide to have the abdominal organs examined only and not have incisions in the head or chest, as well as external, placental and x-ray examinations.
3. External examination only – you may decide to consent to only an x-ray and external examination of your baby's body and the placenta, and not allow any incisions. This means that the pathologist would not be able to examine any internal organs.
4. Step-wise examination – in this examination, restrictions are placed and further investigation is conducted only if initial findings suggest that there may be irregularities elsewhere. For example, if you permit a step-wise examination of the abdomen due to a condition affecting this area and the pathologist finds clear indications that the condition has also affected the chest, the chest will then be examined.

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The level of information obtained by a post-mortem examination depends upon how complete the examination is, and the actual cause of death. The greater the information, the better your doctor or caregiver may explain how your baby died and if this will affect future pregnancies or the health of your other children. However, even in a full autopsy the cause of death may not be able to be determined.

What happens to my baby's organs?

In most cases during an autopsy in which a baby's organs are examined, the organs are replaced intact following investigation. However, in some circumstances, it is considered necessary to take a small tissue sample to examine the cells and tissue under a microscope. This part of the examination is called a histological analysis and will be included in the autopsy report. The tissue sample is approximately one cubic centimetre, or the size of a small pea. If a problem is found with the tissue sample, a more detailed investigation may be required.

Some organs, such as the brain, are unable to be examined properly without 'fixation', which is a chemical treatment that increases the amount of information that can be found. If you give permission for fixation, the organ may be retained for up to a week. This may affect funeral arrangements for your baby. In these circumstances you may either:

- a) delay cremation or burial until the examination is complete and your baby's body is completely restored.
- b) continue with funeral arrangements and have a separate burial or return of cremated organs at a later time.

All decisions are entirely up to you, although your doctor, pathologist or caregiver may be able to

assist, providing information and support through this difficult process.

What can I expect after the examination?

It is usually possible for you to see and hold your baby after an autopsy. Usual changes occur once a baby has died, such as a change in skin colour and body temperature, however there are also some changes due to the examination. The changes will depend on which procedures have been conducted. Where internal organs have been examined, you can expect to see the presence of stitches (or sutures), which are usually under the baby's clothing. You may also notice that the balance of your baby's head and body has changed. You may get more information about seeing and holding your baby following a autopsy from nursing staff, the hospital social worker, or your funeral director. They may also be able to describe your baby's appearance to you, or dress your baby to cover any sutured lines if you prefer.

When can I expect the results from the autopsy?

After any autopsy, the pathologist writes a report, which details all of his or her findings. This report is then sent to the doctor who cared for your baby.

Generally a preliminary report will be available within two to three weeks. Once all test results are known, a final report is forwarded to your doctor. This may take several months following a baby's death.

The information in the post-mortem report may assist your doctor in providing the cause of your baby's death, implications for future pregnancies or the health of existing children and assist in appropriate referral to relevant professionals, such as a Genetic Counsellor.

Parents need to be aware that in some instances the autopsy results will not be able to explain the cause of your baby's death.

How do I know if I am making the right decision?

There is no right or wrong decision regarding consent to a autopsy of your baby's body. For many parents it is a very difficult and personal decision which takes into account many factors and considerations, including religious, cultural and personal beliefs.

Family and friends may offer their advice and opinions about autopsy, or be opposed to your decision. It is important to remember that, although their perspective is suitable for them, the decision is yours.

Do I need to make any decisions right now?

No. You may prefer to keep this brochure and discuss the options with your doctor or with the pathologist before making a decision. It may take time before you decide. Delaying an autopsy may result in less accurate information being obtained, however this may not be the case. Further information regarding timeframes can be obtained from your doctor or from the nursing staff.

Who can I contact for further information?

For further information and/or support in your decision, please contact:

- SANDS/SIDS & Kids (whichever is relevant for each state)
- Your General Practitioner or Obstetrician.

Section 3; Appendix 2 Information for parents about autopsy

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 an 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.

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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 www.psanz.org.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, SIDS and Kids information – whichever is relevant in each state.

*See PSANZ Perinatal Mortality Audit Guideline, Section 3 for list of references. More Brochures are available at www.psanz.org.au under Perinatal Mortality Special Interest Group.

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