



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

3.1	Role of health professionals	57
3.2	Breaking bad news	58
3.3	Environment for care	59
3.4	Understanding parental loss and grief.....	59
3.5	Termination of pregnancy	60
3.6	Perinatal palliative care.....	62
3.7	Birthing options	62
3.8	Sedation/pain relief options	64
3.9	Seeing and holding a stillborn baby.....	64
3.10	Memory creation	66
3.11	End of life decision making.....	67
3.12	Autopsy/post-mortem	68
3.13	Caretaking of the baby’s body and funeral arrangements.....	69
3.14	Special circumstances	70
3.15	Aftercare	71
3.16	Health care professionals.....	72
3.17	References.....	74

Appendices

Appendix 1; Information for parents about autopsy	69
Appendix 2; Information for the health professional seeking consent.....	71

SECTION 3 PSYCHOLOGICAL AND SOCIAL ASPECTS OF PERINATAL BEREAVEMENT

Introduction

For parents the experience of stillbirth or neonatal death is usually unexpected and devastating. The death of a baby at or around the time of birth is one of the most significant life events an adult will face, and for staff caring for these families, it can be both challenging and rewarding. For parents, the suddenness of the event and the challenge to the 'natural order' of life is confronting.⁽¹⁾ Although many parents anecdotally report they will grieve a life-time for a deceased child, most of them will find healing over time. Providing compassionate care of families at the time of perinatal loss can be challenging in busy maternity settings. Some of the barriers that have been identified include health care provider discomfort, consistency of care, lack of adequate training, and cultural and legal issues. Recommendations for best practice include consistent and clear communication, supported decision-making; evidence based physical and emotional care and follow-up.⁽²⁾

3.1. Role of health professionals

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.^(3, 4) Inadequate training in loss and grief in undergraduate programs resulting in staff being unprepared for dealing with death, grief and loss in their work is well documented.⁽⁵⁾ Professional, cultural and societal assumptions of parental grief can influence the quality of emotional care provided by health professionals who may 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.

The role of health practitioners in the handling of death and their interaction with bereaved individuals can influence the intensity of grief.^(3, 4) Grief can be significantly reduced when practitioners involve families in medical decisions related to the dying or deceased person's care.⁽³⁾ Studies have examined important factors in caring for bereaved parents.^(3, 4, 6-9) Skilled, sensitive and caring treatment around the time of a pregnancy loss can positively impact on the grief experience of bereaved parents.^(3, 6) Collaborative decision-making can help reduce regret and remorse.^(2, 10) Key aspects of care identified include: validation and acknowledgement of parent's physical and emotional experiences; sharing of knowledge; memory creation; 'empowerment' and the provision of 'safe' and sensitive care.⁽¹¹⁾ It is important that clinicians accept a wide range of responses in bereaved parents and do not project their own values or expectations upon those in their care.⁽¹²⁾ Studies that have identified a range of concerns in the care of bereaved parents include disempowerment of parents, insensitive and unsympathetic care,⁽³⁾ lack of validation of physical and emotional experiences and lack of knowledge.^(3, 6, 8)

A recent Cochrane review concluded that there is insufficient information available from randomised controlled trials (RCTs) to indicate benefit in certain interventions which aim to provide psychological support or counselling for mothers, fathers or families after perinatal death; however it identified a range of qualitative and quantitative studies that can contribute to recommendations for care, particularly in the hospital setting. It also recommended that methodologically rigorous trials be undertaken.⁽²⁷⁾

The following information is provided as a guide to assist clinicians in providing a range of support strategies for families within the hospital setting and after discharge, including bereavement support and counselling, multidisciplinary follow-up, and subsequent pregnancy care.

3.2. Breaking bad news

The importance of individualised care that focuses on relational care-giving which acknowledges the uniqueness of each patient and their family, respects culture and encourages collaborative decision making is key to communicating with grieving parents, ⁽¹²⁾ particularly when the news is sudden or unexpected.

Even when bad news is delivered well we are not able to eliminate the pain and distress for parents, however we know that if bad news is communicated poorly, it is likely to increase the immediate and long-term distress of parents. Parents report that when they are treated with respect and sensitivity, and the 'bad news' is delivered with warmth and affection, positive memories are created. ⁽¹¹⁾

Elements of good communication include:

- Use a phrase as a prelude to prepare parents for bad news such as: "I am afraid I have bad news" Or "I am sorry to have to tell you this...." This helps parents to be more ready to hear the news.
- Parents need time to take in the information and to formulate questions and express concerns.
- Information should balance honesty with realism, sensitivity and support.
- Avoid using medical terminology.
- Communicate clearly (do not use euphemisms).
- Tell parents when there is uncertainty
- Collaborate in decision-making.

Parents' responses can include shock and disbelief, distress, anger, blame, guilt or tears. For health professionals who are used to fixing problems, it can be difficult to witness the raw emotions of grief, and to feel powerless to 'solve' the situation, which can result in parents' emotions 'shutting down', which is usually not helpful. Crying or other intense reactions may need to be released, and parents will value a staff member who can remain calm and supportive, allowing parents to express their thoughts and feelings. Once the initial flood of emotion has passed, it is usually possible to discuss with parents what needs to happen next. Parents will need impartial and objective information in order to make decisions that are good for them in both the short-term and long-term. ⁽¹¹⁾ Staff should ensure they have considered their own values and opinions, and that these are not imposed upon or unduly influence grieving parents. ⁽¹³⁾ Encouraging parents' autonomy in decision making can be beneficial in grief in the long-term. ⁽¹¹⁾

Cacciatore ⁽¹⁴⁾ offers the following recommendations in communicating with bereaved parents:

- Don't interrupt the speaker and allow for time between thoughts
- Avoid coming to conclusions too quickly
- Stay attentive and engaged
- Listen for cues about feelings, beliefs and ideas
- Avoid offering impulsive reactions or solutions

- Pay attention to what the person is saying
- Be respectful in non-verbal, as well as verbal, communication
- Accept the emotional sentiment of the parent
- Listen attentively
- Avoid paternalistic responses, which are inconsistent with a woman-centered approach to care ⁽¹⁴⁾

McDonagh et al ⁽¹⁵⁾ found that a direct correlation between the proportion of time the family spoke and the physician listened resulted in increased satisfaction about the meeting, better impressions of the physician, less conflict and a greater sense that the family's needs were being met.

Parents can have difficulty absorbing and retaining information when bad news is given to them. It is useful therefore to reinforce verbally given information with a fact sheet or written information that is relevant to the parents, their baby and their loss.

The National Health and Medical Research Council has produced general guidelines to assist clinicians in effective communication. ^(16, 17)

3.3. Environment for care

The environment for care of bereaved parents varies dependant on the setting and model of care. The main aim is to provide an environment that balances the need for privacy for the family, and access to appropriately trained staff for clinical care, support and guidance. In some settings, mothers are offered the option to be cared for in an area separate to the maternity ward; however it should not be assumed this is suitable for all, as it may further create isolation or reinforce a sense of failure. If it is possible, a purpose built room, separate from busy birth suites/wards is ideal, which ensures access to staff to provide the necessary physical and emotional care of the family, and privacy. Where possible a setting that has the facility for extended family members to gather is important, particularly for families where extended family involvement in grief is valued (e.g. Indigenous, Mouri and South-Sea Islander).

In the case of a dying neonate, a room connected to the nursery, or a perinatal loss unit where staff are accessible to the family while care is redirected, or palliative care provided, can ensure the family are well supported during the difficult time of the baby's impending death and afterwards. Thought should be given to the possibility of providing perinatal palliative care in the family home, if this is something that is possible and desired by the family. Some families report feeling quite fearful about taking their baby home to die. It is important if a palliative plan is put in place that parents are clearly informed about who to contact if they need assistance. Access to care that is available 24 hours/day is essential. Some parents have indicated their preference for palliative care in the home rather than hospital when they are well supported to take a dying baby home. ^(18, 19)

3.4. Understanding parental loss and grief

Although loss and grief is predominately a normal experience, for many parents, facing the death of their baby will be their first experience of the death of a close family member. Consequently they may have little knowledge of or preparation for what to expect and how to manage the intense experience of parental grief. Attachment theory provides an understanding of the nature of human relationships as well as the nature of grief and

mourning. Bowlby's⁽²⁰⁻²³⁾ theory of attachment between the mother and infant provided a basis for further understanding of the nature of relationships between two people, and the reaction when loss of the relationship was threatened.

From a loss perspective, the loss of attachment is at the core of parental grief.⁽²⁰⁾ Maternal attachment to the developing baby during pregnancy is enhanced by interactions between the mother and child which include planning, confirming and accepting the pregnancy, feeling the baby move, accepting the baby as an individual, birthing, seeing and touching the baby and caretaking the baby. More recently the impact of medical technology on attachment has been recognized. With the advance of high definition imaging in pregnancy ultrasounds, parents 'meet' their unborn baby long before birth, often on multiple occasions, enhancing the identity and therefore the attachment to the baby. This can further add to the intensity of the grief when the child is stillborn or dies soon after birth. Prenatal diagnosis, including use of ultrasound, amniocentesis and chorionic villi sampling (CVS) has been found to increase feelings of guilt when parents are faced with having to make decisions for their unborn child, which may include terminating the pregnancy.⁽²⁴⁾ In caring for women and their partners who experience pregnancy loss, it is important to remember that it is the degree of investment in the pregnancy rather than the duration of the pregnancy that relates to the intensity of grief. Therefore gestational age is not a good predictor of parental grief intensity.⁽²⁴⁾

A deep respect for, and knowledge of the process of attachment and grief can guide endeavours to care for families when a baby dies. Rather than negating relational bonds, a more considered response is to acknowledge and support the parent-infant relationship. Parents may only have hours or days with a child who is stillborn or dies shortly after birth. Activities such as spending time with the baby, making care-related decisions, taking photographs and other memorabilia will be important considerations. Introducing the baby to the extended family, holding a 'baptism' or 'blessing' or naming service and making decisions about autopsy and funeral arrangements after death are important parenting activities. These tasks are not just important in order to create memories or mementos, but to create a lifelong bond with the child that can endure beyond death.^(25, 26) Cacciatore^(27, 28) encourages 'enhanced understanding' of the experience of loss, so that parents' loss is validated and legitimized, and parents are provided unconditional support from hospital caregivers. She suggests such care can enhance parents' *'lifelong experience of grieving and re-grieving, understanding and re-understanding, as new associated meanings of the baby's death emerge and evolve.'* In this way staff can assist families to create and enhance a lifetime relationship with the baby.

A comprehensive discussion of parental grief is not possible within the context of these guidelines. Further reading is recommended from the references list at the end of the chapter or more in-depth guidelines such as *Pregnancy loss and the death of a baby: SANDS Guidelines for professionals*⁽²⁹⁾ or the Cochrane Review: *Support for mothers, fathers and families after perinatal death.*⁽³⁰⁾

3.5. Termination of pregnancy

The availability of early antenatal screening and testing provides parents with information of the potential risks and/or diagnosis of foetal abnormality in the first or second trimester of pregnancy. Such testing may provide parents with an opportunity to make decisions regarding continuation of the pregnancy, potentially preventing the birth of a child with a debilitating disease. Such decisions involve complex ethical, legal and social issues

including the grief associated with the loss of a 'normal' child⁽³¹⁾ as well as the potential for complicated grief.^(32, 33)

Although some suggest there is limited value in provision of prenatal testing if the option of termination is unacceptable,⁽³⁴⁾ others take a different view, arguing that ethical decision making is a complex phenomenon and information about the baby and options for management enables good moral-decision making. The diagnosis of a lethal foetal anomaly, regardless of the decision to continue with the pregnancy or not, is associated with multiple losses. Parents grieve the loss of a healthy baby, the loss of a normal pregnancy experience and the loss of the hoped for future with the child. Parents report the importance of feeling like 'real parents' for the short time they have but are often disconnected from family and friends who struggle to understand them. Other reported difficulties include the fragmented health system, where lack of continuity, misinformation, lengthy waiting times for results and 'uncomfortable interactions' with health care providers add to the difficulty of the journey. Overall, the experience can be one of isolation and loneliness where lack of understanding and sensitivity contributes to the pain of grief.⁽³⁵⁾

Parents need sensitivity and compassionately provided information to enable them to understand the medical condition of the child in order for them to make an informed decision. Continuity of care and counselling that provide hope balanced with prognostic uncertainty is valued, as is a non-judgemental attitude when families do make decisions. Timing of information should minimize unnecessary delays.⁽³⁵⁾

A few studies have explored the specific interventions that may be beneficial in supporting grief for couples who choose to end a pregnancy due to foetal anomaly. Some early studies, based on the implied value of contact with a deceased baby, recommended contact with the foetus, grieving rituals and memory creation.^(36, 37) A more recent comprehensive meta-analysis however explored specifically the issue of viewing the foetus following termination of pregnancy for foetal anomaly and concluded that there is an absence of empirical evidence to guide recommendations, and cautioned that care should be taken in suggesting benefit, as the evidence does not support such claims. Rather than health professionals encouraging women and their partners to see the foetus because of their own, or their institution's particular beliefs and practices, the author recommends they (health professionals) remain mindful of motives, personal opinions or routines that may impose practices that are not evidence-based, and respect the choice of couples who conclude that viewing is not appropriate for them.⁽³⁸⁾

An important aspect specific to the grief of termination of pregnancy for foetal anomaly is the many paradoxes women face: they are caught between seeing the termination of pregnancy as an act of love as opposed to choosing to 'kill' their baby; the loss of being a parent to this child as opposed to the feeling of not being able to parent a child with significant abnormality; the relief of having technology which can identify foetal anomalies however resenting the technology that puts them in such a difficult position, and the wanting and hoping that others won't judge them, while judging themselves.⁽³⁹⁾

Women who undergo termination of pregnancy for foetal abnormality experience significant grief, particularly within the first 4-6 months. A key factor is the loss of a hoped for pregnancy. Although the majority of women recover and adapt well to the loss, a small number regret their decision, and some will develop complicated grief, including post-traumatic symptoms and depression.⁽⁴⁰⁻⁴²⁾ A pilot study of women undergoing termination of pregnancy for foetal abnormality revealed intense grief and a degree of enduring

posttraumatic stress responses still detectable 2-7 years after the procedure. ^(32, 43) The authors suggest care needs to be improved through better preparation of women choosing termination of pregnancy, development of specific grief interventions, as well as encouragement of physicians and other health carers to inform women that the loss is a significant one, and that it may have lasting implications. ^(32, 43)

3.6. Perinatal palliative care

Perinatal palliative care may be a considered approach to care in the circumstances where the baby is to be born at a pre-viable gestation, where there is an antenatal diagnosis of life-limiting foetal anomalies, or where there is a postnatal diagnosis appropriate for palliative care. Couples who choose to continue with the pregnancy after the diagnosis of foetal anomalies face a difficult and challenging pregnancy. Some have reported less than satisfactory care from their health team including feelings of abandonment.⁽⁴⁴⁾ Misunderstanding, miscommunication, apathy, and even hostility from medical professionals have been described.⁽⁴⁵⁾

Perinatal palliative care is an emerging area of care which aims to address the issues of caring for a mother and baby with a fatal or life-limiting condition. For some, it provides an alternate option to termination of pregnancy. A palliative care plan may be developed during the antenatal period, if it is known that the baby has a life-limiting condition. Involvement of the multidiscipline team is important, so that parents can be well-informed in their decision making.^(18, 46)

The overall goal of perinatal palliative care is the provision of individualized, seamless care irrespective of the time of day, location of the unit, presence of team members or the gestational age of the baby.⁽⁴⁷⁾ In some cases, it is not possible to determine the likely eventual outcome of the baby's problems, and so decision-making is guided by the degree of certainty of the diagnosis, the certainty of the prognosis and the meaning that the prognosis has for the parents.⁽⁴⁷⁾ The structured and compassionate care that is embodied in perinatal hospice can be provided alongside mainstream pregnancy care to facilitate the challenging task of assisting families to cope with the dying and death of their baby with comfort and dignity. Care that acknowledges and supports anticipatory grief can assist in lightening the burden of post-death bereavement.⁽⁴⁸⁾

Although no quantitative empirical studies have determined the best model of care for perinatal palliative care, a small number of clinical studies have identified key components of care, including early and interactive care in the antenatal period, a family-centred approach and comprehensive care from a multi-disciplinary team including a bereavement specialist. A systematic review of the literature on the provision and availability of perinatal hospice or palliative care services reports uptake rates between 37% to 87%.⁽⁴⁹⁾ Comprehensive perinatal palliative care guidelines have been developed to inform best practice in this area of care

http://www.bapm.org/publications/documents/guidelines/Palliative_Care_Report_final_%20Aug10.pdf

3.7. Birthing options

Because the timing and mode of birth following the diagnosis of an intrauterine foetal death (IUFD) is dependent on a variety of factors, management should be individualized. Most women opt for delivery within 48 hours of the diagnosis often due to the emotional

difficulty of carrying a dead baby.⁽⁵⁰⁾ Going home for a period of time before birth can give parents time to consider the information they have received, share the news with extended family or other children and gather support.

A study of 314 women who had experienced an IUID explored the relationship between timing of delivery and maternal anxiety. They found that postponing the delivery without consultation with the women contributed to unnecessary psychological distress. The time from diagnosis of death in utero to the start of the delivery process appeared to have a dose related effect on anxiety with 23% of women who waited more than 24 hours scoring high anxiety. When compared with women who delivered within 6-24 hours, those who delivered later had a fivefold increased risk of long-term anxiety related symptoms. It was thought that the strong association was potentially related to the psychological trauma of carrying a dead baby, which increases with duration.⁽⁵¹⁾ Timing of the birth can be delayed for longer if the mother requests, with regular physical monitoring and surveillance being recommended.⁽⁵⁰⁾

The mode of birth will be dependent on the gestational age of the foetus and maternal clinical history, with consideration of the woman's personal preference. Options should be discussed to determine the best (safest) decision for each individual woman, as no one mode of delivery has been shown to provide better physical or grief outcomes. If the pregnancy loss is early, medical management or surgical management (dilation and curettage [D&C]) are offered, whereas a later foetal demise will necessitate either an induction or augmentation of labour or in some instances a caesarean section. A significant advantage of the medical management of induction of labour over surgical management is the delivery of an intact baby, providing parents the choice of seeing and holding the infant and making decisions about autopsy, which may be particularly important if the cause of death is 'unexplained'.⁽⁵²⁾

In the case of a previous caesarean section, management must be individualized, but generally women with a previous lower segment incision and a uterine size of less than 28 weeks can be offered a prostaglandin (misoprostol) induction of labour. If the uterus is greater than 28-week size, induction with cervical ripening and/or oxytocin has been recommended. There is limited data for women with a prior classic uterine incision.⁽⁵⁰⁾ Some women may elect a repeat caesarean, but should be counselled regarding the risks and benefits. Although couples facing the shock of diagnosis of foetal death report initially that they consider a caesarean the best option,⁽⁵³⁾ women who do not have a clinical indication for caesarean delivery should be strongly encouraged to reconsider, and reassurance given that pain relief and physical and emotional support during the labour and birth will be provided.

Trulsson and Radestad (2004) interviewed women about their mode of birth following the diagnosis of an IUID. They reported the initial shock experienced by mothers who perceived the plan to have a vaginal birth as 'appalling'; however after delivery they described a feeling of achievement, and acknowledged that they would not have wanted their delivery to be different.⁽⁵⁴⁾ When partners were asked about the mode of delivery following diagnosis of an IUID, the majority of men initially thought that caesarean section should be performed, and reported feeling repulsed with the idea that his partner should have to undergo the physical pain and distress of a vaginal delivery. Despite this initial reaction, all later reported that vaginal birth was a positive experience, with the natural procedure conveying more dignity. Some men also valued their role in supporting their partner during the labour and birth.⁽⁵⁵⁾ The importance of good communication and

collaborative decision-making between couples and their carers is essential.

In all circumstances where options are available, the benefits and risks of each mode should be explained to the parents. For example, a baby with a life-limiting condition may not survive a labour and natural birth, however may be born alive if delivered by caesarean section. This may be particularly important for a couple who wish to spend the short amount of time they may have with their child or to ensure they are the ones who hold their child while he/she is dying. In such instances it is important that staff inform parents of the risks of caesarean section and the consequences for future pregnancies/births.^(56, 57)

3.8. Sedation/pain relief options

Only a small number of studies have explored options for pain relief for women who experience stillbirth. A meta-analysis of hospital care after perinatal loss⁽⁵⁸⁾ identified seven small mostly qualitative studies that explored pain management during labour and birth. Findings indicate that pain relief is often inadequate, however 41% of parents reported that sedation was often over-used leading to feelings of regret.⁽⁵⁹⁾

A large anonymous national survey of obstetricians in the United States revealed that 48.5% agreed or strongly agreed in the use of sedatives for a grieving mother in acute bereavement care,⁽⁶⁰⁾ even though there is no evidence for its benefit in either improvement in sleep or grief⁽⁶¹⁾ and there exists significant evidence about the potential addictive nature of this group of medications.⁽⁶²⁾ Raphael et al (2001) strongly recommend that pharmacological approaches to intervening in grief should only be provided to those for whom there is an established disorder where medication is indicated.⁽⁶²⁾

Although there has been a gradual growing of acceptance for the use of the birthing pool to provide pain relief in low risk pregnancies generally, this mode of delivery is not frequently considered for women who have a diagnosis of IUFD. A recent case study described the potential advantages of this method of pain management, including a more relaxed and less clinical environment, enhanced sense of control, and greater opportunities for support persons to be involved. They conclude that labour and delivery in the birthing pool could be considered as an additional option for women with IUFD where no other contraindications exist.⁽⁶³⁾

3.9. Seeing and holding a stillborn baby

One of the most important decisions facing parents when a baby is stillborn is whether or not they will see and hold the infant and engage in other contact with the deceased baby, although controversy continues over this component of care. Parents may initially be hesitant or fearful of seeing their deceased baby, and will look to staff for advice and support. Unfortunately the literature is confusing in this area, and there is no simple recommendation to guide parents. A recent meta-analysis of 34 studies related to the issue of seeing and holding a stillborn baby, reported a variety of factors associated with the decision. Mothers are more likely to see their baby than fathers,⁽⁶⁴⁾ and parents are more likely to see and hold their infants when the death occurs in the third trimester when compared with earlier losses.⁽⁶⁵⁾ Although maceration is often cited as one of the reasons for concern about seeing a deceased infant, this is not supported by research; however parents of babies with malformations are less likely to see the baby.^(64, 66) Consistently reported is that nearly all parents who see their baby find the experience valuable and one

they would not have wanted to forego. Many report that they would have liked to have had more opportunity to see their baby. Even parents who were initially hesitant, later reported seeing and holding the baby to be a good choice, and expressed a desire to have spent even more time.⁽⁶⁷⁾ It is possible that contact intensifies attachment, which is not regretted by parents who believe that *'some degree of psychological morbidity is a price worth paying for such a highly valued experience.'*⁽⁶⁸⁾ The majority of parents who decline to see or hold their baby later express regret, and have reported that they may have reconsidered their choice if the invitation had been provided more than once.^(65, 67) When the choice of whether or not to see or hold a dead infant occurs within a "social and cultural context" that emphasises the importance of acknowledging and confronting feelings rather than suppression or avoidance, then the invitation is more likely to be accepted.⁽⁶⁹⁾

Although seeing and holding a stillborn baby has become almost 'standard practice' in many maternity settings, some caution still needs to be taken. . . A study of primigravid mothers who experienced a stillbirth suggested behaviours that promoted contact with a stillborn infant (seeing and holding) were associated with worse psychological outcomes. When compared with mothers who did not hold their infant, women who did were more likely to be depressed, experience anxiety and have higher symptoms of PTSD in the third trimester of the pregnancy. By one-year post delivery, these symptoms were no longer significant; however these mothers demonstrated a trend towards 'disorganised attachment' at one year.⁽⁷⁰⁾ Follow-up of the mothers at 7 years indicated that higher rates of PTSD persisted over time.⁽⁶⁹⁾ This study has been heavily criticised by both bereaved parents and researchers who feel that the translation of the study results to all women should be made with caution due to issues with cohort representation, small sample size and the lack of detail provided around how women were presented with (the option of seeing or holding) their stillborn baby.^(71, 72) Careful preparation of both the deceased baby and the parents who choose to view a deceased baby is vitally important. If this is not attended with sensitivity and an understanding of trauma prevention, the risk of development of trauma symptomatology is more likely.⁽⁷³⁾

Radestad and Christoffersen (2008) suggest that the time immediately after the birth of a stillborn baby may be the ideal time for seeing and holding, while the baby is still warm and before the post-mortem changes take effect. A cohort of Swedish mothers who had experienced stillbirth in 1991 was studied at approximately 3 years post death to determine the long-term outcome after having held or not having held a stillborn baby. Of the 314 women who participated, only 14 mothers did not see their baby at all, 99 saw but did not hold their stillborn infant, and 210 held their baby. No significant detriment in terms of anxiety or depression (as measured with standardized anxiety, depression and quality of life questionnaires) was found in mothers who had experienced a late stillbirth (37 weeks onwards) and who had held their baby, whereas 17% of women who had not seen their baby scored over the 90th percentile in depression measures at 3 years. Somatic complaints were also reported by women who did not hold their baby. The conclusion drawn by the authors is that seeing and holding provides an overall benefit through enhancing the mother's attachment to her baby, which in turn facilitates a healthy mourning process.⁽²⁷⁾

One study (Hughes et al (ref) reported some women in their study felt 'coerced' by staff to have contact with their baby when they had declined. Also, consideration should be given to the importance of cultural and religious preferences and practices that may influence families' decisions to have contact with their deceased baby.⁽⁷⁴⁾ There is limited research to support staff in providing information on various culturally and linguistically diverse

communities with particular reference to perinatal death. Until further evidence through high quality studies can determine the best interventions for couples regarding seeing and holding a stillborn infant, it is recommended that clinicians should err on the side of caution and assist parents in making an informed choice as to what is right for them, after being provided information.^(30, 75-78)

3.10. Memory creation

There is general consensus of opinion that parents should be offered items of memorabilia such as photos, hand/footprints and special clothing or blankets when a baby dies.^(11, 50, 51, 58) The collecting of such items does not appear to lead to adverse grief outcomes⁽⁷⁰⁾ whereas not having such items has been linked to increased anxiety in mothers of stillborn babies.⁽⁵¹⁾ A meta-analysis of hospital care for parents after a perinatal loss found that parents overwhelmingly appreciated having photos and memorabilia of the deceased baby, and frequently expressed regret if these were not provided by the hospital.⁽⁵⁸⁾ Fathers reported that tokens of remembrance were invaluable, and were appreciative of staff collecting them, even if they were declined.^(51, 55)

3.10.1. Photographs

Several studies have specifically explored the value or otherwise of the taking of photographs of dying or deceased babies, reporting them to be highly valued by parents. The quality of the photograph is important. Women who had a satisfactory photograph of their stillborn baby reported fewer symptoms of anxiety three years after the birth. Quality may be affected by technique and the timing of the photograph after the baby's death.⁽⁷⁵⁾ For photos to serve as treasured memories and facilitate future grieving,⁽⁷⁹⁾ it is essential that they are quality images. They should capture the baby in natural positions, including being held and wherever possible, conceal disfigurements. It is important to sensitively seek the couple's permission for their baby to be photographed.⁽⁸⁰⁾ A range of photographs should be considered including:

- The baby individually as well as with parents (and extended family if suitable)
- Images of babies together if the death is one or more of a multiple pregnancy (this may necessitate discussion with staff in critical care nurseries if one or more baby is born alive)
- Photos with mementoes such as quilt, teddy, special clothes, etc
- Photographs during the birth (if appropriate).

Some maternity units have links with professional photographers to ensure quality photos.

3.10.2. Mementoes

A range of mementos can be provided to families including:

- Hand and footprints or castings of hands and/or feet
- Baby identification bracelet and cot card
- Digital photographs and/or video of the baby's birth and afterwards (printed, saved to CD/DVD)
- Lock of hair (where possible and only after permission of the parents has been given)
- Measuring tape
- Clothes or memory quilt used by baby
- Baptism certificate or naming service sheet

- Memory Box, Teddies, Hearts, Angels, etc
- Grief Pack
- Special care nursery equipment, such as BP cuff, CPAP fixatives, eye masks

3.10.3. Baptism/Blessing/Naming service

Many parents value the opportunity for a formal blessing, baptism or naming service for their child. Arrangements for the pastoral care staff or a hospital Chaplain or religious representative should be made available. Where a baby is in the Critical 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. Timing of the baptism can be critical in some instances.

In creating any mementoes, it should be remembered that these tangible reminders of the baby are to help to create continuing bonds for the parent, helping to provide solace in their memories of their child.⁽²⁶⁾ Therefore the quality and sensitivity of such mementoes is important.

3.11. End of life decision making

Perhaps the most difficult decision of all faced by some parents is to have to choose whether or not to initiate resuscitation, continue with active intensive care, or to redirect care to comfort care. Supporting parents in end of life decision making requires clear, compassionate communication, physical and emotional support, collaborative decision making and follow up care that recognizes and addresses the medical, psychological and social aspects of the baby's life and death and the parents grief.⁽²⁾ Involvement of parents in discussions and decisions to withhold or withdraw intensive care of critically ill newborns has not been found to aggravate or prolong parental grief or increase the incidence of grief pathology.⁽⁸¹⁾

A model of shared decision-making, based on a mutual discussion of 'goals of care' for a dying baby can assist staff and families in engaging in difficult conversations. Such an approach focuses on the parents' hopes for the child and considers the family's value system. The role of the health professionals is to explore with the family if their goals are realistic, or if they may involve an excessive burden of care on the baby. This model gives equal weight to both the family and the medical team, and often reduces the potential of conflict.⁽⁸²⁾

Discussing possible options for involvement in the baby's dying, preparation for the death and guided decision-making are important aspects of care.^(83, 84) A study of the perspectives of 15 parents regarding withdrawal of life support in the neonatal setting found that none expressed guilt over their decision to remove life support from a critically ill infant, believing that it was 'the right thing to do.' Nonetheless they did express regrets about how they spent time with the baby after having made this decision. Parents are often not in the position to consider their needs or the importance of memory making at this time. Discussing involvement in the baby's dying, preparation for the death and guided decision-making are important aspects of care.^(81, 83, 84)

Effective pain and symptom management is of paramount importance in the relief of

potential suffering for the baby, as well as existential distress for the family. It is important to note that neither the adult or neonatal literature has demonstrated that the use of narcotics and sedatives reduces the time to death. This is an important reassurance for both parents and staff who may find this aspect of care ethically concerning.⁽⁸⁵⁾ Parents also need information and support in understanding the dying process, in particular the agonal respirations with long periods of apnoea that occur in the final stage. By the time the baby experiences this breathing pattern he/she is invariably unconscious, and as such the breathing pattern is reflexive and consequently should not be a source of discomfort.⁽⁸⁵⁾

Staff caring for the baby should offer parents the opportunity to have maximum contact with their baby during this process, if they desire. Parents' requests should be respected, and all efforts made to make the experience as compassionate, sensitive and meaningful as possible. Privacy without isolation is essential along with staff focus on compassionate, supportive and empathic care. Respect for the baby and his/her life and respect for the intensity of parental grief are crucial.

The timing of the death is frequently uncertain even after life-sustaining treatment is withdrawn, and parents may become distressed when their baby continues to live for some time, outside their expectations. They may question their decision and feel uncertainty about 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 decision to provide palliative comfort care has been made. In some instances it may be possible for the parents to take the baby home as long as suitable community palliative care services are available.

3.12. Autopsy/post-mortem

The decision about whether or not to have an autopsy after a baby has died can be a confronting one for parents. International concern has been raised about relatively low perinatal autopsy rates, citing a range of reasons including health system issues and parental concerns.⁽⁸⁶⁾ Although controversy over past practices of organ retention, complex consenting problems,⁽⁸⁷⁾ and lack of staff knowledge and confidence⁽⁸⁸⁾ have been identified as barriers to autopsy, a range of parental factors also contribute to the final decision.

Parents who have a greater desire for information about their baby's death are more likely to consent to an autopsy. The majority of parents who do consent to an autopsy have an expectation that it will assist in determining the reasons why the baby died. Altruism is also an important factor in choosing an autopsy, where parents hold hope that the results may be able to assist other families or prevent the same tragedy from occurring to others. Autopsy findings have also been reported to assist mothers in their grief. The findings can help to validate the decision made by mothers who have had a termination of pregnancy for foetal abnormalities, and relieve self-blame in mothers who may have attributed their baby's problems to their own behaviours.⁽⁸⁹⁾ A small number of parents report regret about their decision in relation to autopsy, including both those that did, and did not consent, though the suggestion from available studies is that decision regret may be more likely when autopsy was not conducted⁽⁹¹⁾

Although some studies have found 'barriers' to autopsy related to religious or cultural restrictions, timing of the funeral or concerns about what will happen to the baby, these have not always been found to contribute significantly to parental decisions.⁽⁸⁹⁾

Knowledgeable clinicians with good communication skills have consistently been identified as an important factor in parental decision-making in relation to autopsy. Midwives were found to be influential in maternal decision-making, and so recommendations have been made that midwives become better informed about autopsy procedures and outcomes.⁽⁸⁸⁾ Senior medical staff should take leadership in supporting prenatal autopsy⁽⁹¹⁾ and junior staff need to be well-trained in seeking autopsy consent, procedures related to post-mortems and explanation of findings.⁽⁹⁰⁾

Parents should be provided with verbal and written information regarding their options for autopsy examination. The health care professional discussing post-mortem with the parents should have developed a rapport or relationship, and/or be a senior clinician with advanced knowledge of post-mortem. Sufficient time should be allocated to explain the options available and to address questions. Parents should be informed that a decision is not required immediately, and a plan made for further discussion. It may be beneficial for parents to have a support person present when the discussion is held. In some cultures it is important to include 'elders' who may play an important role in decision making for the family.

Personal contact with the perinatal pathologist undertaking the examination, if available, may assist in addressing specific questions both before and after autopsy.⁽⁹²⁾ In any case, assurance should be given that the baby will be treated with respect and dignity. Parents should also be informed that they have the option to have contact with (see and hold) their baby after the autopsy has been completed. It is important for parents to be informed about how long the baby will be away from them (including timing for funeral arrangements), any transport arrangements, and when and how the results will be made available to them.

(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.)

3.13. Caretaking of the baby's body and funeral arrangements

Parents should be informed that it is a legal requirement that the body of a deceased baby (who is greater than 20 weeks gestation) is buried or cremated. In most instances these arrangements need to be made with a registered funeral company or crematorium. Parents are not legally required to arrange a funeral or other service, however the value of such rituals in the perinatal loss setting has been acknowledged.⁽⁹³⁾

Some parents may wish to take their baby to their family home prior to the burial or cremation for cultural ceremonies or just to have this time as a family. Hospitals should have some processes in place to support families who make such requests. Some considerations include instructions to parents on how to take care of the body (e.g. ice packs, air-conditioning, cold cots), arrangements with a funeral company, and instructions regarding documents such as the death certificate. Muslim families may also request the baby's body is collected by a family member rather than a funeral company to attend to the ritual washing at the mosque prior to burial.

Provision of written information which includes funeral company contact details and options is valuable for parents. Funeral companies vary widely in the range of services they provide, and parents should be advised that they can have access to their baby after

discharge from hospital. Options may include returning to the hospital or attending the funeral home. Parents may want to consider bathing and dressing their baby, placing the baby in the coffin or spending time together before the funeral. It should be reinforced that there is no urgency for parents to make the arrangements or hold a service or funeral, and by taking some extra time, they may feel more prepared to do this.

The cost of funeral services varies greatly, and may be burdensome for some families. The government provides financial support in some circumstances. Information regarding this and other benefits is available from Centrelink.

3.14. Special circumstances

3.14.1. 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
- 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. 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
- possible benefits of autopsy for the surviving child/ren
- memory creation that acknowledges the multiple pregnancy ⁽⁹⁴⁾

The grief of mothers who experience the loss of a twin or higher order multiple has been found to be at the least as significant as the loss of a singleton baby, and in some mothers higher, due to the disenfranchisement of their grief. ⁽⁹⁵⁾

3.14.2. 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, transfer to another hospital). Where possible, efforts should be made to provide an opportunity for access to her baby during and/or after maternal recovery.

If possible the baby should remain in the hospital mortuary 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 videotaping the baby with family members may be beneficial to the mother.

3.14.3. 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 resurgence of the previous loss and grief, which can add to or complicate the current loss.⁽⁹⁶⁾ Some parents may have clear ideas regarding the way in which they choose to manage the death of their baby due to their prior experience. This may include the creation of memories and the way in which they choose 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. Referral for psychological support should be considered with recognition of the complex nature of multiple losses.⁽⁹⁷⁾

3.15. Aftercare

3.15.1. Maternal changes

Mothers should be informed that their milk may 'come in' following a stillbirth, or if feeding has already been established with the baby, then lactation may need to be suppressed. This experience can be both physically painful and emotionally distressing for a woman. Management options for lactation include the use of medication for lactation suppression and simple comfort measures. A consultation with a lactation consultant if available may be helpful. Mothers also need to know about other post-pregnancy physical 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).

3.15.2. Psychological support services for parents and siblings

There are differing views on the value of bereavement interventions for individuals experiencing normal grief.^(98, 99) However recent studies have identified the value of interventions for individuals experiencing complicated grief.⁽¹⁰⁰⁾ Alternate viewpoints suggest that early intervention and prevention in mental health can prevent long-term psychological morbidity.^(101, 102) This lack of clear evidence is confusing for clinicians, but more concerning can leave bereaved parents with inadequate support or recommendations at one of the most difficult and distressing times of life. Providing parents with a list of peer support groups such as SANDS (Stillbirth And Neonatal Death Support Group), SIDS and Kids, and SAFDA (Support After Foetal Diagnosis of Abnormality), or websites as well as encouragement to keep contact with their primary care provider (e.g. community midwife, health nurse, GP) can be a good first step in assisting parents to find appropriate support when needed. Specialised perinatal loss and grief counselling may be provided by a psychologist or bereavement counsellor.

Siblings can experience significant losses when a baby dies within the family, and recognition of these losses is important within the hospital setting and in the following months.⁽¹⁰³⁻¹⁰⁵⁾ It can be suggested to parents that they inform the school principal and/or counsellor of the death of the baby, so that support can be made available if needed.

3.15.3. Follow up appointment

A follow-up appointment with the multi-disciplinary team including senior obstetrician and/or neonatologist should be offered to all families who experience a perinatal loss, ^(2, 11, 106) ideally within 6-8 weeks following the death. The venue for this meeting should be carefully considered, recognizing the psychological impact of returning to the hospital, and potentially the confronting nature of being around pregnant women and newborns early in grief. Elements of the follow up appointment should include:

- discussion of events leading up to the baby's death
- discussion regarding decisions and interventions provided during the mother's episode of care
- results of maternal clinical investigations and perinatal post-mortem investigations
- implications for future pregnancies
- referral for further testing or consultation if needed (e.g. Geneticist)
- discussion of parent's grief and coping and recommendations or referral for on-going support if necessary

3.15.4. Subsequent pregnancy following loss

The vast majority of couples who experience a perinatal loss will, at some time in the future, consider a subsequent pregnancy. In the past, concerns about a 'replacement pregnancy' resulted in clinicians cautioning mothers to wait for some time before conceiving another pregnancy, however there is no empirical evidence for this. Studies that have explored timing of a subsequent pregnancy concluded that mothers themselves are the best 'judge' when they are emotionally ready for a new pregnancy.⁽¹⁰⁷⁾

The subsequent pregnancy itself presents a range of issues and challenges for parents. Feelings of heightened anxiety, fear, worry, reticence and scepticism have been reported ^(108, 109) as has restrained expectations due to fear of a recurring loss, guarded emotions, resurgent grief, insecurity, hyper-vigilance and a range of attachment concerns and issues. ^(68, 110, 111) Recommendations for care of women and partners in a subsequent pregnancy include: continuity of care, sensitivity to milestones during the pregnancy, dealing with heightened anxiety, collaborative problem solving, recognition for the need for additional appointments and good communication skills. ^(112, 113)

3.16. 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.^{(3),(114)} 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. Opportunities for debriefing or clinical supervision should be considered for staff who deal regularly with perinatal loss, as have been found to be beneficial in preventing burnout of staff working in highly emotionally demanding roles.^(115, 116)

Imaging staff are often the first practitioners to discover abnormalities that are incompatible with life or that a baby has died in utero. Their training should include an understanding of loss and grief, and basic skills in empathic communication. The social work role too has been identified to be a key role in some perinatal loss settings.^(12, 14)

Section 3 Guideline updates.

Acknowledgment is made to those who have significantly contributed to the review and update of this section of the guidelines.

First edition: Kylie Lynch, Liz Davis, Sonia Herbert, Ros Richardson, Dell Horey, Vicki Flenady

Second edition (minor review): Liz Davis, Ros Richardson and Vicki Flenady

Third edition (major review): Trish Wilson, Belinda Jennings, Diana Bond, Paula Dillon, Fran Boyle

3.17. References

1. Keesee NJ, Currier JM, Neimeyer RA. Predictors of grief following the death of one's child: the contribution of finding meaning. *Journal Of Clinical Psychology*. 2008;64(10):1145-63.
2. Williams C, Munson D, Zupancic J, Kirpalani H. Supporting bereaved parents: practical steps in providing compassionate perinatal and neonatal end-of-life care. A North American perspective. *Seminars In Fetal & Neonatal Medicine*. 2008;13(5):335-40.
3. Corbet-Owen C, Kruger, M. The health system and emotional care: validating the many meanings of spontaneous pregnancy loss. *Families, Systems and Health*. 2001;19:411-27.
4. Prigerson HG, Jacobs SC. Perspectives on care at the close of life. Caring for bereaved patients: "all the doctors just suddenly go". *Jama*. 2001 Sep 19;286(11):1369-76.
5. Breen LJ, O'Connor M. The Fundamental Paradox in the Grief Literature: A Critical Reflection. *Omega: Journal of Death & Dying*. [Article]. 2007;55(3):199-218.
6. DeFrein J. Learning about grief from normal families: SIDS, stillbirth, and miscarriage. *Journal of Marital Therapy*. 1991;17:215-39.
7. DeFrein J, Millspaugh, E, Xie, S. The psychosocial effects of miscarriage: Implications for health professionals. *Families, Systems and Health*. 1996;14:331-47.
8. Lee C, Slade P. Miscarriage as a traumatic event: a review of the literature and new implications for intervention. *J Psychosom Res*. 1996 Mar;40(3):235-44.
9. Rando T. The unique issues and impact of the death of a child. Champaign, IL: Research Press; 1986.
10. Rosenbaum JL, Smith JR, Zollfrank R. Neonatal end-of-life spiritual support care. *The Journal Of Perinatal & Neonatal Nursing*. 2011;25(1):61-9.
11. Henley A, Schott J. The death of a baby before, during or shortly after birth: Good practice from the parents' perspective. *Seminars in Fetal and Neonatal Medicine*. 2008;13(5):325-8.
12. Cacciatore J, Bushfield S, Cacciatore J, Bushfield S. Stillbirth: the mother's experience and implications for improving care. *Journal Of Social Work In End-Of-Life & Palliative Care*. 2007;3(3):59-79.
13. Williams C, Alderson P, Farsides B. Is nondirectiveness possible within the context of antenatal screening and testing? *Social Science & Medicine*. 2002;54(3):339-47.
14. Cacciatore J. Stillbirth: patient-centered psychosocial care. *Clinical Obstetrics And Gynecology*. 2010b;53(3):691-9.
15. McDonagh JR, Elliott TB, Engelberg RA, Treece PD, Shannon SE, Rubenfeld GD, et al. Family satisfaction with family conferences about end-of-life care in the intensive care unit: increased proportion of family speech is associated with increased satisfaction. *Critical Care Medicine*. 2004;32(7):1484-8.
16. National Health and Medical Research Council. Communicating with patients: advice for medical practitioners. Canberra: Commonwealth of Australia 2004.
17. National Health and Medical Research Council. General guidelines for medical practitioners on providing information to patients. Canberra: Commonwealth of Australia 2004.
18. Leuthner S, Jones EL, Leuthner S, Jones EL. Fetal Concerns Program: a model for perinatal palliative care. *MCN, American Journal of Maternal Child Nursing*. 2007 Sep-Oct;32(5):272-8.
19. Roy DJ. When newborn babies have to die... perinatal palliative care? *J Palliat Care*. 2007;23(2):67-8.
20. Bowlby J. *Attachment & Loss*: Pimlico; 1969.
21. Bowlby J. The making and breaking of affectional bonds. I. Aetiology and psychopathology in the light of attachment theory. An expanded version of the Fiftieth Maudsley Lecture, delivered before the Royal College of Psychiatrists, 19 November 1976. *The British Journal Of Psychiatry: The Journal Of Mental Science*. 1977;130:201-10.
22. Bowlby J. Attachment theory and its therapeutic implications. *Adolescent Psychiatry*. 1978;6:5-33.
23. Bowlby J. Attachment and loss: retrospect and prospect. *The American Journal Of Orthopsychiatry*. 1982;52(4):664-78.
24. Robinson M, Baker L, Nackerud L. The relationship of attachment theory and perinatal loss. *Death Stud*. 1999 Apr-May;23(3):257-70.

25. Klass D. Continuing Conversation about Continuing Bonds. *Death Studies*. 2006;30(9):843-58.
26. Klass D. *The Spiritual Lives of Bereaved Parents*. Neimeyer RA, editor. Philadelphia: Brunner/Mazel; 1999.
27. Radestad I, Christoffersen L. Helping a woman meet her stillborn baby while it is soft and warm. *British Journal of Midwifery*. 2008;16(9):588-91.
28. Cacciatore J. The unique experiences of women and their families after the death of a baby. *Social Work in Health Care*. 2010;49(2):134-48.
29. Schott J, Henley A, Kohner N. *Pregnancy loss and the death of a baby: guidelines for professionals*. Stillbirth & Neonatal Death Charity (Sands), UK. 2007.
30. Koopmans L, Wilson T, Cacciatore J, V F. Support for mothers, fathers and families after perinatal death. *Cochrane Database of Systematic Reviews*. 2013(6).
31. Sandelowski M, Barroso J. The travesty of choosing after positive prenatal diagnosis. *JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing*. 2005;34(3):307-18.
32. Kersting A, Dorsch M, Kreulich C, Reutemann M, Ohrmann P, Baez E, et al. Trauma and grief 2-7 years after termination of pregnancy because of fetal anomalies--a pilot study. *Journal Of Psychosomatic Obstetrics And Gynaecology*. 2005;26(1):9-14.
33. Korenromp MJ, Page-Christiaens GCML, van den Bout J, Mulder EJH, Hunfeld JAM, Potters CMAA, et al. A prospective study on parental coping 4 months after termination of pregnancy for fetal anomalies. *Prenatal Diagnosis*. 2007;27(8):709-16.
34. Ekberg M. Maximizing the benefits and minimizing the risks associated with prenatal genetic testing. *Health, Risk & Society*. [Article]. 2007;9(1):67-81.
35. Cote-Arsenault D, Denney-Koelsch E. "My baby is a person": parents' experiences with life-threatening fetal diagnosis. *J Palliat Med*. 2011;14(12):1302-8.
36. Kolker A, Burke B. Grieving the wanted child: Ramifications of abortion and prenatal diagnosis of abnormality. *Health Care for Women International*. 1993;14(5):513-526.
37. Furlong R, Black R. Pregnancy termination for genetic indications. *Social Work in Health Care*. 1984;10(1):17-34.
38. Sloan E, Kirsh P, Mowbray M. Title Viewing the fetus following termination of pregnancy for fetal anomaly. [Review] [47 refs]. *JOGNN - Journal of Obstetric, Gynecologic, & Neonatal Nursing*. 2008;37(4):395-404.
39. Vantine H. *Terminating a wanted pregnancy after the discovery of possible fetal abnormalities: An existential phenomenological study of making and living with the decision*. 2000.
40. Kersting A, Reutemann M, Ohrmann P, Baez E, Klockenbusch W, Lanczik M, et al. Grief after termination of pregnancy due to fetal malformation. *Journal Of Psychosomatic Obstetrics And Gynaecology*. 2004;25(2):163-9.
41. Zeanah CH, Dailey JV, Rosenblatt MJ, et al. Do women grieve after terminating pregnancies because of fetal anomalies? A controlled investigation. *Obstetrics And Gynecology*. 1993 August;82(2):270-5.
42. Korenromp MJ, Page-Christiaens GC, van den Bout J, Mulder EJ, Hunfeld JA, Potters CM, et al. A prospective study on parental coping 4 months after termination of pregnancy for fetal anomalies. *Prenat Diagn*. 2007 Aug;27(8):709-16.
43. Kersting A, Kroker K, Steinhard J, Burgoine GA, Romm J. Does abortion technique influence the course of perinatal grief in second trimester termination for fetal anomalies?... Burgoine GA, Van Kirk SD, Romm J, Edelman AB, Jacobson SL, Jensen J. Comparison of perinatal grief after dilation and evacuation or labor induction in second trimester terminations for fetal anomalies. *Am J Obstet Gynecol* 2005;192:1928-32. *American Journal of Obstetrics & Gynecology*. 2006;194(6):1743-4.
44. Leuthner SR, Pierucci R. Experience with neonatal palliative care consultation at the Medical College of Wisconsin-Children's Hospital of Wisconsin. *Journal of Palliative Medicine*. 2001;4(1):39-47.
45. Wilkinson DJC. Antenatal diagnosis of trisomy 18, harm and parental choice. *Journal Of Medical Ethics*. 2010;36(11):644-5.
46. Munson D, Leuthner SR. Palliative care for the family carrying a fetus with a life-limiting diagnosis. *Pediatr Clin North Am*. 2007 Oct;54(5):787-98, xii.

47. Kobler K, Limbo R. Making a case: creating a perinatal palliative care service using a perinatal bereavement program model. *J Perinat Neonatal Nurs*. 2011 2011 Jan-Mar;25(1):32-41.
48. Hoeldtke NJ, Calhoun BC. Perinatal hospice. *Am J Obstet Gynecol*. 2001 Sep;185(3):525-9.
49. Balaguer A, Martin-Ancel A, Ortigoza-Escobar D, Escribano J, Argemi J. The model of Palliative Care in the perinatal setting: a review of the literature. *BMC Pediatrics*. 2012;12:25-.
50. Silver RM, Heuser CC. Stillbirth workup and delivery management. *Clinical Obstetrics And Gynecology*. 2010;53(3):681-90.
51. Radestad I, Steineck G, Nordin C, Sjöågren B. Psychological complications after stillbirth--influence of memories and immediate management: population based study. *BMJ (Clinical Research Ed)*. 1996;312(7045):1505-8.
52. Silver RM. Fetal death. *Obstetrics And Gynecology*. 2007;109(1):153-67.
53. Samuelsson M, Radestad I, Segesten K. A waste of life: fathers' experience of losing a child before birth. *Birth (Berkeley, Calif)*. 2001;28(2):124-30.
54. Trulsson O, Radestad I. The silent child -- mothers' experiences before, during, and after stillbirth. *Birth: Issues in Perinatal Care*. 2004;31(3):189-95.
55. Samuelsson M, Radestad I, Segesten K. A waste of life: fathers' experience of losing a child before birth. *Birth: Issues in Perinatal Care*. 2001;28(2):124-30.
56. Villar J, Carroli G, Zavaleta N, Donner A, Wojdyla D, Faundes A, et al. Maternal and neonatal individual risks and benefits associated with caesarean delivery: multicentre prospective study. *BMJ*. 2007 2007-11-15 00:00:00;335(7628):1025.
57. Lydon-Rochelle M, Holt VL, Easterling TR, Martin DP. Risk of Uterine Rupture during Labor among Women with a Prior Cesarean Delivery. *New England Journal of Medicine*. 2001;345(1):3-8.
58. Gold KJ, Dalton VK, Schwenk TL. Hospital care for parents after perinatal death. *Obstet Gynecol*. 2007b May;109(5):1156-66.
59. Harper MB, Wisian NB. Care of bereaved parents. A study of patient satisfaction. *Journal of Reproductive Medicine*. 1994 Feb;39(2):80-6.
60. Gold KJ, Schwenk TL, Johnson TR, Gold KJ, Schwenk TL, Johnson TRB. Brief report: sedatives for mothers of stillborn infants: views from a national survey of obstetricians. *Journal of Women's Health*. [Research Support, Non-U.S. Gov't]. 2008 Dec;17(10):1605-7.
61. Warner J, Metcalfe C, King M. Evaluating the use of benzodiazepines following recent bereavement. *Br J Psychiatry*. 2001;178:36-41.
62. Raphael B, Minkov C, Dobson M. Psychotherapeutic and pharmacological intervention for bereaved persons. In: Stroebe MS, editor. *Handbook of bereavement research : consequences coping and care*, . Washington DC: United States American Psychological Association; 2001. p. 587-612.
63. Stocks LPJ, Rowland JS, Martindale EA, Heazell AEP. The use of the birthing pool after a diagnosis of stillbirth. *Journal Of Obstetrics And Gynaecology: The Journal Of The Institute Of Obstetrics And Gynaecology*. 2010;30(2):200-1.
64. Rand CS, Kellner KR, Revak-Lutz R, Massey JK. Parental behavior after perinatal death: twelve years of observations. *Journal Of Psychosomatic Obstetrics And Gynaecology*. 1998;19(1):44-8.
65. Lasker JN, Toedter LJ. Satisfaction with hospital care and interventions after pregnancy loss. *Death Stud*. 1994 Jan-Feb;18(1):41-64.
66. .
67. Radestad I, Surkan PJ, Steineck G, Cnattingius S, Onelov E, Dickman PW. Long-term outcomes for mothers who have or have not held their stillborn baby. *Midwifery*. 2009 Aug;25(4):422-9.
68. Turton P, Badenhorst W, Hughes P, Ward J, Riches S, White S. Psychological impact of stillbirth on fathers in the subsequent pregnancy and puerperium. *Br J Psychiatry*. 2006 Feb;188:165-72.
69. Turton P, Evans C, Hughes P. Long-term psychosocial sequelae of stillbirth: phase II of a nested case-control cohort study. *Arch Womens Ment Health*. 2009 Feb;12(1):35-41.
70. Hughes P, Turton P, Hopper E, Evans CD. Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study. *Lancet*. 2002 Jul 13;360(9327):114-8.

71. Schott J, Henley A. Pregnancy loss and death of a baby: the new Sands Guidelines 2007. *British Journal of Midwifery*. 2007;15(4):195-8.
72. Badenhorst W, Hughes P. Psychological aspects of perinatal loss. *Best practice & research. Clinical obstetrics & gynaecology*. 2007.
73. Bennett SM, Litz BT, Maguen S, Ehrenreich JT. An Exploratory Study of the Psychological Impact and Clinical Care of Perinatal Loss. *Journal of Loss and Trauma*. 2008;13:485-510.
74. Chichester M. Multicultural issues in perinatal loss. *AWHONN Lifelines*. 2005 Aug-Sep;9(4):312-20.
75. Schott J, Henley A. After a stillbirth -- offering choices, creating memories. *British Journal of Midwifery*. 2009 12;17(12):798-801.
76. NICE. NICE set to change its advice on holding stillborn babies. *Paediatr Nurs*. [Article]. 2010;22(2):5-
77. Hutti MH. Social and professional support needs of families after perinatal loss. *J Obstet Gynecol Neonatal Nurs*. 2005 Sep-Oct;34(5):630-8.
78. Cunningham KA. Holding a stillborn baby: does the existing evidence help us provide guidance? *The Medical Journal Of Australia*. 2012;196(9):558-60.
79. Klass D, Silverman PR, Nickman SL. *Continuing bonds: New understandings of grief*. Klass D, Silverman PR, Nickman SL, editors: Philadelphia, PA, US: Taylor & Francis; 1996.
80. Mander R, Marshall RK. An historical analysis of the role of paintings and photographs in comforting bereaved parents. *Midwifery*. 2003;19(3):230-42.
81. Schulze A, Wermuth I. [Compassionate care for terminally ill term and preterm infants]. *Zeitschrift F r Geburtshilfe Und Neonatologie*. 2007;211(2):54-9.
82. De Lisle-Porter M, Podruchny AM, De Lisle-Porter M, Podruchny AM. The dying neonate: family-centered end-of-life care. *Neonatal Network - Journal of Neonatal Nursing*. [Practice Guideline]. 2009 Mar-Apr;28(2):75-83.
83. Armentrout D. Living with grief following removal of infant life support: parents' perspectives. *Critical Care Nursing Clinics Of North America*. 2009;21(2):253-65.
84. Kaempf JW, Tomlinson MW, Campbell B, Ferguson L, Stewart VT. Counseling pregnant women who may deliver extremely premature infants: medical care guidelines, family choices, and neonatal outcomes. *Pediatrics*. 2009;123(6):1509-15.
85. Munson D. Withdrawal of Mechanical Ventilation in Pediatric and Neonatal Intensive Care Units. *Pediatric Clinics of North America*. 2007;54(5):773-85.
86. Flenady V, Middleton P, Smith GC, Duke W, Erwich JJ, Khong TY, et al. Stillbirths: the way forward in high-income countries. *The Lancet*. 2011;377(9778):1703-17.
87. Khong TY, Tanner AR. Foetal and neonatal autopsy rates and use of tissue for research: the influence of 'organ retention' controversy and new consent process. *J Paediatr Child Health*. 2006 Jun;42(6):366-9.
88. Khong TY, Turnbull D, Staples A. Provider attitudes about gaining consent for perinatal autopsy. *Obstet Gynecol*. 2001 Jun;97(6):994-8.
89. Breeze ACG, Statham H, Hackett GA, Jessop FA, Lees CC. Perinatal Postmortems: What Is Important to Parents and How Do They Decide? *Birth*. 2012;39(1):57-64.
90. Rankin J, Wright C, Lind T. Cross sectional survey of parents' experience and views of the
91. Horey, D., Flenady, V., Conway, L., McLeod, E. and Yee Khong, T. (2012), Decision influences and aftermath: parents, stillbirth and autopsy. *Health Expectations*. doi: 10.1111/j.1369-7625.2012.00782.x postmortem examination. *BMJ (Clinical Research Ed)*. 2002;324(7341):816-8.
91. Putman MA. Perinatal perimortem and postmortem examination: obligations and considerations for perinatal, neonatal, and pediatric clinicians. *Adv Neonatal Care*. 2007 Dec;7(6):281-8.
92. Holste C, Pilo C, Pettersson K, Radestad I, Papadogiannakis N. Mothers' attitudes towards perinatal autopsy after stillbirth. *Acta Obstetrica et Gynecologica Scandinavica*. 2011;90(11):1287-
93. Hoffnung M. Soothing parental grief by helping construct rituals for stillborn babies. *PsycCRITIQUES*. 2008;53(8).
94. Kollantai JA. Loss and Grief in Twin Pregnancy and Birth. *International Journal of Childbirth Education*. 2012;27(2):39-43.

95. Swanson PB, Pearsall-Jones JG, Hay DA. How mothers cope with the death of a twin or higher multiple. *Twin Research: The Official Journal Of The International Society For Twin Studies*. 2002;5(3):156-64.
96. Stroebe M, Hansson R, Schut H, Stroebe W. *Handbook of Bereavement Reserach and Practice*. Washington, DC: American Psychological Association; 2008.
97. Rando TA. *Treatment of Complicated Mourning*. Champaign, IL: Research Press; 1993.
98. Neimeyer RA. Grief counselling and therapy: the case for humility. *Bereavement Care*. 2010;29(1):4-7.
99. Larson DA, Hoyt WT. What has become of grief counseling? An evaluation of the empirical foundations of the new pessimism. *Professional Psychology: Research and Practice*. 2007;38(4):347-55.
100. Shear MK, Simon N, Wall M, Zisook S, Neimeyer R, Duan N, et al. Complicated grief and related bereavement issues for DSM-5. *Depression and Anxiety*. 2011;28(2):103-17.
101. Mrazek PJ, Haggerty RJ. *Reducing Risks for Mental Disorders: Frontiers for Preventive Intervention Research*. Mrazek PJ, Haggerty RJ, editors. Washington, D.C.: National Academy Press; 1994.
102. Raphael B, Wooding S. Early mental health interventions for traumatic loss in adults. In: Litz BT, editor. *Early intervention for trauma and traumatic loss*. New York, NY US: Guilford Press; 2004. p. 147-78.
103. Avelin P, Erlandsson K, Hildingsson I, R√•destad I. Swedish parents,Ä• experiences of parenthood and the need for support to siblings when a baby is stillborn. *Birth: Issues in Perinatal Care*. 2011;38(2):150-8.
104. Callister LC. Perinatal loss: a family perspective. *J Perinat Neonatal Nurs*. 2006;20(3):227-36.
105. Sandler CL, Robinson E, Carter BS. Loss in the NICU: Sibling Matters. *The American Journal Of Hospice & Palliative Care*. 2012.
106. McHaffie HE, Laing IA, Lloyd DJ. Follow up care of bereaved parents after treatment withdrawal from newborns. *Arch Dis Child Fetal Neonatal Ed*. 2001 Mar;84(2):F125-8.
107. Radestad I, Hutti M, Saflund K, Onelov E, Wredling R. Advice given by health-care professionals to mothers concerning subsequent pregnancy after stillbirth. *Acta Obstet Gynecol Scand*. 2010 Mar 15.
108. Côté-Arsenault D, Mahlangu N. Impact of perinatal loss on the subsequent pregnancy and self: Women's experiences. *Journal of Obstetric, Gynecologic, and Neonatal Nursing. JOGNN - Journal of Obstetric, Gynecologic, & Neonatal Nursing*. 1999;28(3):274-82.
109. Lamb EH. The impact of previous perinatal loss on subsequent pregnancy and parenting. *Journal of Perinatal Education*. 2002;11(2):33-40.
110. Armstrong DS. Emotional distress and prenatal attachment in pregnancy after perinatal loss. *J Nurs Scholarsh*. 2002;34(4):339-45.
111. Armstrong DS, Hutti MH, Myers J. The influence of prior perinatal loss on parents' psychological distress after the birth of a subsequent healthy infant. *J Obstet Gynecol Neonatal Nurs*. 2009 Nov-Dec;38(6):654-66.
112. Hughes P, Cockburn J. The Next Pregnancy After Stillbirth Psychological Challenges in Obstetrics and Gynecology. In: Cockburn J, Pawson ME, editors.: *Springer London*; 2007. p. 193-208.
113. Caelli K, Downie J, Letendre A, Caelli K, Downie J, Letendre A. Parents' experiences of midwife-managed care following the loss of a baby in a previous pregnancy. *Journal of Advanced Nursing*. 2002 Jul;39(2):127-36.
114. Davis CG, Wortman CB, Lehman DR, Silver RC. Searching for meaning in loss: are clinical assumptions correct. *Death Stud*. 2000 Sep;24(6):497-540.
115. Begley C. 'I cried ... I had to ... ': student midwives' experiences of stillbirth, miscarriage and neonatal death. *Evidence Based Midwifery*. 2003;1(1):20-6.
116. Davidson JE, Powers K, Hedayat KM, Tieszen M, Kon AA, Shepard E, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. *Crit Care Med*. 2007 Feb;35(2):605-22.

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 navel, 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.

Section 3; Appendix 2 Information for parents about autopsy

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 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

Section 3; Appendix 2 Information for parents about autopsy

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 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.

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.