

Guidelines for health care professionals supporting families experiencing a perinatal loss

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Principal author(s)

J van Aerde; Canadian Paediatric Society, [Fetus and Newborn Committee \(https://www.cps.ca/en/documents/authors-auteurs/fetus-and-newborn-committee\)](https://www.cps.ca/en/documents/authors-auteurs/fetus-and-newborn-committee)

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"Bereaved parents never forget the understanding, respect, and genuine warmth they received from caregivers, which can become as lasting and important as any other memories of their lost pregnancy or their baby's brief life."
[1]

Despite the lack of evidence from randomized trials that providing specific psychological support or counselling after perinatal death has any effect on the prevention of pathological grieving or long term psychosocial morbidity [2], an empathetic, caring environment that facilitates a mother's and family's acceptance of the reality of death are now part of standard perinatal care and support [3]. This statement provides insights into the phases, and processes of grieving and mourning, especially the unique aspects of pregnancy loss and neonatal death. Based on descriptive studies and common sense practice, general guidelines for caregivers are provided, with more specific suggestions for special conditions.

Definitions

Loss

Two categories of loss exist: physical and symbolic losses. A physical loss is the loss of something tangible, and often others recognize physical losses. In contrast, a symbolic loss is the loss of something intangible (divorce, retirement, the development of chronic illness, shattered dreams), which is seldom recognized by others as a loss generating feelings that require processing [4].

Grief

Grief refers to the process of experiencing psychological, behavioural, social and physical reactions to loss. It is a continuing process involving many changes over time. It is a natural reaction, and its absence may be abnormal and indicative of pathology. It is a reaction to all types of loss, not just death, and it is dependent on an individual's unique perception of loss and does not need social recognition or validation by others (ie, it is the specific subjective feeling that accompanies a loss) [4][5].

Mourning

Mourning is the cultural and/or public display of grief through one's behaviour. It is the process through which the resolution of grief may be accomplished.

Bereavement

Bereavement is the entire process precipitated by the loss of a loved one through death [5].

Three phases of grief and mourning

Avoidance or protest

Avoidance or protest covers the period during which the news of death is initially received and the time briefly thereafter. Generally, it lasts for a few hours to several days. It is marked by the understandable desire to avoid the terrible acknowledgement that a loved one is lost, and by a desperate and frantic attempt to reinstitute the relationship with the lost person. Anger and hostility frequently are present during the initial phase of mourning, and may be directed at health care workers or toward oneself, specifically for having failed to do something to avert the loss [4][5].

Confrontation and disorganization

The phase of confrontation and disorganization is a time when grief is experienced most intensely, and reactions to the loss are most acute; it introduces awareness of finality. This is a painful, internal phase when the mourner confronts the reality of the loss and gradually absorbs its meaning. The most characteristic feature of this phase is preoccupation with thoughts of the deceased while the mourner relives his or her relationship with the lost one. These memories are intrusive and painful, but they constitute the necessary grief work that eventually helps the mourner to relinquish the important attachment [4]-[6].

Accommodation or reorganization

During the accommodation and reorganization phase, there is a gradual decline in the symptoms of acute grief, and the beginning of social and emotional reinvestment in the world. The deceased or the loss is not forgotten, but the mourner learns to live with the cognizance of the death and its implications in a way that does not preclude a healthy, life-affirming growth. This process, which extends for at least one to two years, indicates the completion of mourning because the person enjoys life again and begins looking toward the future [4][5].

The normal grieving process after a child's death: The unique aspect of neonatal death

The death of an infant is a profound loss, and it is important and advantageous to acknowledge families' appropriate need to grieve for their babies. The death of a baby is especially difficult to endure because parents envision an entire lifetime for their baby from the moment of the confirmation of the pregnancy, and because their expectations and vision have been built over time (Table 1). With the death of their baby, parents lose an entire future. Parents also grieve for the loss of their own parenthood [7]. Kowalski [8] states that perinatal death represents multiple losses to parents, including the loss of a significant person, the loss of some aspect of the self, the loss of external objects, the loss of a stage of life, the loss of a dream and the loss of creation. Culturally, a couple whose first pregnancy ends in a loss has not completed the rite of passage into parenthood, which symbolizes adult status [9].

TABLE 1

Psychological process of becoming a parent

- Feelings of procreativity and generativity
- A sense of continuity through the generations
- Fears and expectations about the coming baby
- Effect on expectant parents' relationship
- Response to quickening and bodily changes
- Attachment to real and idealized aspects of the infant
- Self-esteem building

The loss of a child is a high risk variable for the development of complicated grieving. It has been documented that, compared with other types of bereavement, parental grieving is particularly intense, complicated and long lasting, with major and unparalleled symptom fluctuations over time [10]. In general, the age of a child is irrelevant in this type of bereavement. Many similar feelings are present for bereaved parents whether the child is two days old, two years old or 22 years old [11]. Many issues centre around the loss of the person who fulfilled a child's role for the parents. Regardless of the child's age, parents have lost their hopes, dreams and expectations for the child. They have lost parts of themselves, each other, their family and their future. Their assumptive worlds have been violated [11].

One has to keep in mind that grief is different for different people. This also applies to both partners of a couple. Often, they cannot synchronize their grieving processes, and this may be a source of interpersonal stress. There is no absolute systematic progression or pattern for every person's response to a baby's death because grief for each individual is intrinsically unique. Although parents struggle over the death of the same child, each partner actually has sustained a different loss and has a unique mourning experience. Normal synchronicity of grief and mourning between two individuals means that bereaved parents are seldom at the same phase of grief at the same time because of their roles in the family, normal fluctuations in grief and differences in how they respond to the different phases of grief [11][12]. Data suggest that the incongruence between spouses dramatically increases from two to four years after the death of a child. After the fifth year, it declines slightly [13].

The process of recovering from the loss of a baby takes time. A period of two to four years seems to be about average for parents, but five or more years of grief is not uncommon. The comparison of study data from both mothers and fathers in several studies makes it apparent that they recover in about the same time [14].

Parental bereavement: An exception to general conceptualizations of mourning

If parental bereavement is analyzed according to the six 'R' processes of mourning [4][12], it is clear that bereaved parents have a number of built-in obstacles to mourning after the loss of a child [15].

- Parents have difficulty recognizing the loss because it violates their basic function as parents and defies the laws of nature; often, social negation of the loss exists. With the loss of pregnancies and the deaths of young infants, no dramatic absence is apparent to signal the loss, causing the parents to have difficulty internalizing the fact that the death has really occurred. Recognizing the loss is also made difficult because the neonatal intensive care unit (NICU) exists to save lives with a technical power that is obvious to the parents.
- Bereaved parents also have difficulty reacting to the separation not in the least because more secondary losses, especially those relating to the self, take place in this type of bereavement.
- Recollecting and re-experiencing the deceased and the relationship is made more difficult for bereaved parents because there is little or nothing concrete to review or remember realistically.
- Relinquishing old attachments to the deceased and the old, assumptive world is difficult because an attachment to the deceased fetus or infant also includes attachments to the self as a parent; and also because relinquishing attachments to the old, assumptive world mandates a complete revision of the most fundamental assumptions of being a parent, and fulfilling parental responsibilities and roles.
- Bereaved parents are compromised in their ability to readjust to the new world without forgetting the old one. Developing a new relationship with the deceased may be difficult because the parental relationship demands role behaviours that are not as amenable as other relationships to a healthy translation on an intrapsychic plane (ie, compared with losing a parent, it is more difficult to retrain internally the role 'to mother' than 'to be mothered' because mothering requires more interactive participation).
- Finally, for the sixth 'R', bereaved parents have more difficulty reinvesting because reinvesting in a similar relationship is more feasible when the relationship is with a spouse, peer or parent than when the relationship is with a child.

What can health care providers do?

Attaching (bonding) and memories

Many actions in the NICU or in the labour and birth area that are taken to facilitate the attachment of the parents with their infant will become memories after a sudden or even an expected neonatal death. Forming an identity for the baby while he or she is alive is an important part of this process, and can be accomplished by using the infant's correct sex and first name, talking to the parents about what the baby likes and dislikes, and describing his or her personality. Holding should be facilitated where possible. Parents should be encouraged to bring in toys, siblings' drawings, family pictures and tapes, which may later serve as mementos. Finally, visiting policies should be around the clock, including during bedside rounds. Over 80% of parents who attended bedside rounds learned new facts about their baby or the NICU, which made them feel more comfortable with the health care team, and there were no complaints about a lack of privacy or confidentiality (unpublished data).

Optimize immediate interaction with parents

Bad news should be given by the attending staff physician in a timely and unhurried manner, and in a private area. Both parents, or one parent with another support person who will stay around for some time after the disturbing information has been delivered, should be present. Whenever possible, the news of impending death should be discussed rather than waiting until death occurs. Parents appreciate and deserve an honest discussion about why their baby died, including a humane overview of the problems, the actions taken and time to allow them to ask questions. By giving complete and understandable information, there is a smaller chance that parents will feel that health care professionals are hiding something from them. Care providers should be understanding and caring, and it is appropriate for them to express empathy, and to show their feelings and concerns.

What to do during the dying process and afterwards

Table 2 presents important actions to be taken during and after the death of a baby. Parents need to spend time with their dying or dead baby. The opportunity to spend time with the baby should be offered on several occasions because some parents may need encouragement. One can ask the parents whether they want to be alone, or to have family or a nurse stay with them; some young parents may be frightened because they have no previous experience with death. Privacy, including privacy for the mother, father and baby as a group, is very important at this stage. This may mean asking additional family members and friends to give the trio some time alone. However, it is important that, at some point, relatives or friends be allowed to see the baby, with the parents' approval. Indeed, these individuals can validate the infant's existence and death, thereby acknowledging the parents' loss and their need for grieving.

TABLE 2

Important actions to take during and after the death of a baby

Assure parents that it is normal to feel uncomfortable at this time

Allow parents to spend as much time as they need with their baby

Make repeated offers for holding the baby

Name the baby

Provide privacy, but do not abandon the parents

Encourage relatives and friends to see the baby, according to the parents' wishes

Warn about gasping and muscle contractions

Reassure parents that their baby was not alone, not afraid and not in pain at the time of death

Reassure parents that nothing more could be done

Provide mementos to create memories

Ensure that spiritual support is available

Take pictures

Explain the need and procedure for an autopsy

Explain options and procedures for memorial services

In no way should the above experience be rushed. Holding the baby should be allowed for as long or as short as the parents wish to do so. One should talk about gasping, muscle contractions and pain or discomfort management beforehand. In the case of a sudden or unexpected death during the parents' absence, one needs to give reassurance that caring individuals held and comforted the baby. In a follow-up contact, these individuals should talk with the parents and offer mementos, which will become very precious to the family. Parents are often concerned that their infant may have experienced fear or pain, and the caregivers need to provide reassurance that those concerns were addressed.

It is critical that every attempt be made for any available family members to spend time with the baby before and after death. Health care professionals have become much better at ensuring that parents spend time with their infant, but the importance of including other family members is less recognized. The grief of parents often is 'validated' when their own parents, siblings, children and close friends can be with the baby, however briefly. Liberal visiting policies in NICUs should facilitate this. It makes sense that people can be more supportive to a family if they also have their own memories of the baby after a long stay in the NICU.

With an infant's death, grandparents mourn the loss of their grandchild and they hurt for their children. Just as the baby's parents need to parent their own child, the grandparents have an urge to parent their children. One has to be careful because such parenting by the grandparents, while well meaning, can deny the baby's parents the opportunity to parent their own infant. After open dialogue among grandparents, parents and, if appropriate, health care providers, reaching a consensus about each other's needs and limits will be to everyone's benefit. However, grandparents' grief is real and should be acknowledged.

Information regarding religious and cultural practices should be sought, and spiritual support from the appropriate religious leader offered. If time permits, any religious ceremony, such as baptism, should be facilitated because this may be an important part of the grieving process for families. If available, bereavement teams may be involved. Autopsy and funeral arrangements should be discussed in definite terms, preferably after the infant has expired, but some families will raise such issues before their baby's death. In neonatal death, the discussion of organ donation,

although often irrelevant, should be mentioned, even if only to say that it is not possible. Finlay and Dallimore [16] have reported that almost two of three patients who were not offered a discussion on organ donation wished that it would have taken place. Finally, flexibility in applying hospital policies is mandatory if they prevent parents from spending time with their dying, or dead infant or child. One has to be sensitive to families with a different cultural background for whom autopsies or withdrawal of aggressive support may be delicate and difficult issues. Discussions with the respective religious leaders may be of help under those conditions.

Nurses and social workers often have the delicate and thoughtful task of collecting mementos such as photographs taken before and after death, ink or plaster foot and handprints, hair, clothing, toys, an identification bracelet, or a record of baby's birth weight and height. Parents should be told why these mementos are being collected to avoid misunderstanding on their part. The manner in which the mementos are given should be compassionate, sensitive and respectful. Small touches are remembered by the parents; for example, in some hospitals photographers are available day and night, free of charge, and social workers provide memory boxes. When all is said and done, do not forget to inform the referring physician(s). A follow-up meeting or phone call with the parents after the funeral will help them come to 'closure', and is mandatory in cases where an autopsy has been performed.

Withdrawal of aggressive support

The actions that are used to facilitate attachment (bonding) will help to build a relationship of trust and understanding. This rapport will instill confidence when discussions about the withdrawal of aggressive life support need to take place. In a way, during the infant's stay in the NICU, the health care team enrolls in a relationship of friendship and caring, and engages in a partnership that respects the needs of the parents to come to decisions that are in the best interest of the infant. With such a mindset, statements may be made, such as "We are doing everything reasonable and possible to help Nina get better, but if she does not respond (by such or such time), we may have to sit down and reconsider what's best for her. And that may include not being so aggressive and letting her go peacefully. We're not there yet, but I'll keep you informed and together we will come to a decision". Not only does this introduce a way for later conversations, it also starts a thinking process in the parents, who themselves may bring up the issue of withdrawal when they notice that their child is not doing well. The concept of a partnership also takes away the burden of parents feeling that they are responsible for the withdrawal of treatment.

The decision to withdraw life support should never rest with the baby's parents so they will not feel responsible for their child's death. One can state that everything possible has been done and nothing more can be done. It may be useful to list the problems and the actions taken to solve the problems. After some kind of statement that "we should consider withdrawing support", one has to ask the parents what they think and believe. Try to keep the burden of the decision away from the parents by emphasizing that everybody (parents and the health care team) has the best interest of the baby at heart, and is trying to come to the best decision for the infant, even if it will cause pain for those making the decision. The attending staff physician should state that the team recommends limitation or withdrawal of support rather than asking the parents what they want to be done. Obtaining a second opinion from another neonatologist may be helpful to reach that goal. Several discussions may have to take place the same day or over a few days. One may advise parents and close relatives to be careful with whom they discuss the exact circumstances of their baby's death because relatively few outsiders will truly understand all the circumstances on which a decision was based without questioning the parents about their agreement to withdraw aggressive support from their baby.

Once the decision to withdraw support is made, explain to the parents precisely how it will happen in practice and offer options so that the parents continue to feel that they are involved in all decisions for their baby until the end. Discussions about the duration of survival, sedation, gasping and muscle contractions should take place before extubation. It is advantageous to remove as much equipment, such as intravenous and arterial lines, chest tubes, urinary catheters and monitors, as possible. It is preferable to dress the infant before the endotracheal tube is removed. Some parents want to hold their baby while he or she is being extubated, and other parents do not. Some parents want to remain at the bedside, which should be screened from other bedsides. Alternatively, parents and the baby can be brought to a quiet room to spend time together, and to respect privacy and confidentiality. The infant can be bag-ventilated while being carried to a quiet room and extubated while in the parents' arms. As discussed before, photographs of the infant before and after extubation, and of the parents holding the infant play a large role in the grieving process later on.

Spirituality and perinatal loss

Spirituality and perinatal loss is discussed in Cunningham [17]. Spirituality is not just a person's religious affiliation. To understand spiritual needs better, health care staff should not limit questions to type of religion or to baptism, but include questions about faith, rituals, traditions, and needs while caring for the infant and the family. Parents' personal spiritual beliefs may not be consistent with the caregiver's own faith tradition, and it behooves the health care provider to find out details and specifics of respective parents' needs and wishes. This clearly implies one cannot impose one's own spiritual values on the family. Finally, the parents' spirituality will influence their emotional, mental and physical responses to bereavement. The health care provider should take the initiative in assessing the spiritual care of families, keeping respect for people and for their spirituality centrally, along with compromises, empathy and listening. Health care professionals can encourage the presence and participation of the family's clergy, and make them feel a part of the perinatal loss bereavement team.

Special conditions

Stillbirth (and miscarriage)

Ryan [7] discusses stillbirth and miscarriage. Emotional bonding occurs well in advance of birth, and parents bring with them expectations and dreams about themselves as parents and about the child that they will have. The lost images and projections constitute major secondary losses, which must be mourned no matter what the age of the child; therefore, even in death before birth, parents lose much [11].

Given the individual circumstances surrounding miscarriage and ectopic pregnancy, stillbirth or neonatal death, any or all of the following may come into play: real (actual) loss of a person, threatened or impending loss of a person, loss of status (motherhood), damaged self-esteem and existential loss. Existential loss associated with pregnancy loss frequently has been overlooked, but it can be summed up by the following: "When your parent dies, you have lost your past. When your child dies, you have lost your future" [18]. Pregnancy loss (miscarriage and stillbirth) has several component losses; not only is there a real and fantasized loss of a baby, but there may also be a significant loss of self-esteem. They include the loss of being pregnant and the sense of oneness with the fetus, the loss of anticipated motherhood and the loss of special attention. The loss of self-esteem results from a woman's inability to rely on her body and successfully give birth. Disruption in functions of self-esteem building related to childbearing are particularly important because they most likely affect this loss in a way that is distinct from other types of bereavement [19]. Pregnancy loss turns a self-enhancing experience into a time of devastation. A closely related phenomenon that occurs in expectant parents whose pregnancy loss is associated with fetal anomalies is the lowering of self-esteem from carrying defective genes.

The circumstances surrounding a stillbirth may prevent a mother, who may be under general anesthesia, from seeing and holding her baby. Sedation and painkillers may make it difficult to remember the experience of the delivery and of holding the dead baby. Whereas these situations should be avoided if at all possible, they may occur and, therefore, it is necessary to have the mother spend enough time with her baby, even if it means several hours after the delivery. Be open, honest and considerate when giving information to parents who experience a perinatal death in the delivery room, including information about religious services such as baptism and spiritual support.

Congenital anomalies

Looking at an infant with anomalies from the perspective of an outsider is very different from seeing that infant from the perspective of a loving parent. Often, parents see the good features, while the deformities or unusual features will not be that important. Many anomalies can be disguised by dressing or wrapping the baby in a blanket, or clothing the infant. Health care professionals may have to encourage parents to spend some time with the baby. It is helpful for the parents to be told that they can name the baby. There is also the need for seeing and holding the baby, and the benefit of taking pictures, and gathering mementos and memories should be emphasized. Finally, a discussion about religious ceremonies, autopsy arrangements and memorial services needs to take place. Sexton and Stephen [20] report that 100% of bereaved mothers who delivered macerated or malformed infants found that seeing and holding the baby after death was helpful.

Twins

Parents have mixed feelings when one twin dies and the other one survives [21]. Just imagine how difficult it must be to rejoice and mourn at the same time. Avoid the common pitfall of regarding the surviving twin as a consolation. A common regret of parents and of the surviving twin is the lack of pictures of the two babies together. Parents who lose one twin may have more difficulty during bereavement than parents losing singleton infants [22]. This is a unique situation with a high risk for a pathological grieving process and, therefore, requires special attention.

Siblings

Depending on their age, siblings may develop some of the same symptoms that parents experience after a perinatal death. Paediatricians and family doctors should understand, and evaluate children's reactions to death by using age appropriate and culturally sensitive guidance while being alert for normal and complicated grief responses [23]. Parents may become overprotective of their children. However, the children may feel pushed away by their parents and, therefore, it is important for parents to spend time with each of their surviving children, and to maintain open and honest communication. Often, siblings will blame themselves because they "wished the baby dead"; others will try to measure up to the lost infant to divert the parents' attention away from the dead baby. Children may be afraid that one of the parents or even they themselves may die next. If the siblings are old enough, they should be included in spending time with their baby after the death and in memorial services.

Expecting and giving birth to an infant with congenital anomalies

With the improvement of antenatal diagnostics, parents may know about abnormalities before delivery, and they may go through grieving earlier than parents who find out about their infant's anomalies after birth. Both types of parents may grieve the loss of what was expected to be a normal baby, and of their hopes and dreams for their baby's future. The grieving feelings may be compounded by guilt about being responsible for the baby's condition and about possible thoughts about wishing the baby would not survive. Early cooperative contacts with individuals in the health care system who will interact with the parents on a long term basis are beneficial.

When parents decide to terminate a pregnancy based on severe anomalies or genetic indications, some believe that they made the right decision, but others continue to experience emotional difficulties. On the one hand, there may be the feeling of relief to have prevented the birth of a severely affected child; on the other hand, there may be a feeling of guilt about having terminated a wanted pregnancy [24][25]. Marital conflict is common, and separation occurred in 12% of couples after a perinatal loss, as reported by Seller et al [25]. There is great variability in the way in which couples respond to pregnancy loss, and problems may well persist six to 12 months after the pregnancy was terminated [26]. Couples should be followed carefully during the period after fetal loss spontaneously or by termination. Even more so than in the case of a neonatal death, men and women grieve differently after pregnancy termination; men usually recover more quickly than women [27], they intellectualize more and keep their feelings to themselves. Women physically experience the pregnancy, while men often feel more like bystanders [28]. This can lead to a lack of synchronicity in the grieving process between the two partners. Factors helpful in dealing with pregnancy termination include recognition, information, communication and hope. Follow-up contacts with a discussion of pathology and genetics are also a part of coming to closure.

Roles of health care providers

Some aspects of this section have been discussed elsewhere in the statement. The roles of the different health care providers overlap in providing bereavement services and counselling. The AAP/ACOG Guidelines for Perinatal Medicine [29] state that the goals of the health care team are to help the family start a normal grief reaction, actualize the loss, acknowledge their grief, assure the family that their feelings are normal and meet the particular needs of each family. Care providers must explore their own attitudes about death and grief, and view them from the perspective of their own culture, including values, beliefs, traditions, and attitudes about health and illness. By recognizing the control that culture superimposes on individuals, providers can better recognize and accept parents' feelings about their baby's death within the parent's own culture. Culture, indeed, influences the meaning of a death for parents and their families, and dictates customs surrounding death [30]. However, regardless of the cultural or religious background, there are certain 'dos and don'ts', as outlined in [Table 3](#).

TABLE 3
'Do's and don'ts'

What to say and do:	What NOT to say or do:
Use simple and straightforward language	Do not say:
Be comfortable showing emotions	"It's best this way"
Listen to the parents and touch the baby	"It could be worse"
"I'm sorry"	"You can have more children"
"I wish things would have ended differently"	"Time will heal"
"I don't know what to say"	"It's good your baby died before you got to know him or her well"
"I feel sad" or "I am sad for you"	Do not use medical jargon
"Do you have any questions?"	Do not argue with parents
"We can talk again later"	Do not avoid questions
Answer questions honestly	

Health care professionals must also remember that the normal grieving process is fluid, with much fluctuation between phases. This fluctuation is universal and does not imply pathology. Staff members supporting grieving families need to assess where the parents are in their mourning process, and then adjust accordingly.

The importance of postmortem evaluation and autopsy needs to be discussed with the parents, particularly because new clinically significant data were discovered by autopsy in up to 44% of cases [31].

Bereavement counselling should be a part of the training program for new health care professionals, who should also have the opportunity to observe senior members of the team. Grieving counselling courses are available in Canada (examples of Web sites are <www.uwo.ca/cstudies/ (<http://www.uwo.ca/cstudies/>)>, and <www.uwo.ca/kings (<http://www.uwo.ca/kings>)>).

The care given to a family before and following a perinatal loss can set the stage for the family's entire grieving process [32]. It is essential that every team member, particularly nurses and social workers, provide compassionate care that meets or exceeds parents' expectations, and the standard of care should be based on the rather limited amount of theory, relevant research and literature available. The most beneficial commodities that a health care professional can offer to a grieving family are a nonjudgmental, deep sense of caring and personal involvement.

Swanson [33] describes five critical attributes of the attentive care provider. A provider who is caring, which is a nurturing way of relating to a valued individual toward whom one feels a personal sense of commitment and responsibility, strives to know; be with; do for; enable the other; and maintain a belief such that, within the

demands, constraints and resources, a path filled with meaning will be chosen.

The first attribute, knowing, means that a provider strives to understand an event as it has meaning in the life of another. By continuously assessing the parents' status and adjusting care appropriately, the care provider will become sensitive and knowledgeable. If this does not happen, the parents' needs are not met by the care provider, and an intrusive, distant or mechanical relationship may ensue [19]. The second attribute of caring, being with or emotionally present to another, means being able to respond to parents' grief and pain without hiding behind the cold, professional approach of 'a job has to be done'. The third attribute, doing for, means doing for parents what one would do for oneself. This includes collecting mementos, taking photographs and encouraging private time with the baby. The fourth attribute, enabling, means facilitating unfamiliar events for the parents by giving anticipatory guidance about events that may occur during the dying process or about memorial services. Finally, maintaining belief, means supporting the parents' capacity to come through this event successfully and to face the future with meaning. One can give hope that different times without the current level of devastation will come once the experience of the baby's death has been integrated into parents' lives. Caregivers who provide this level of care will fulfill the unique needs of grieving parents by assisting them to have positive memories of their baby, and by giving them a feeling of being cared for in the midst of their pain and grief.

Follow-up with the parents after discharge is essential to help maintain the healthy grieving that they started in the hospital. The health care professional or grief counsellor who has been involved most with the parents in the hospital should follow the parents after discharge. Not only does this provide parents a connection with somebody who knew their baby and their circumstances, but it also offers the caregiver feedback regarding the final outcome for these parents, thereby energizing the provider for future families.

Finally, staff members themselves may need a support mechanism to deal with their feelings of loss and grief. A debriefing session for the entire health care team may be appropriate to accomplish this.

Role of the paediatrician, obstetrician and family doctor

Some aspects of the role of the paediatrician, obstetrician and family doctor are shared with other members of the health care team, and the magnitude of the role depends on the degree of involvement with the family before the perinatal loss occurred [7]. The role of the paediatrician or family doctor becomes particularly crucial in a case of neonatal death at home or in an emergency department, where interactions with emergency medical transport personnel and hospital emergency staff have not allowed the building of a progressive relationship as happens when a death occurs in the delivery room or NICU. If the paediatrician or family doctor has had previous contact with the parents, a visit to the hospital before or after the perinatal death and/or a phone call a few days later is very supportive for parents. Plans for an office visit after several weeks are helpful, particularly if the paediatrician or family doctor will be the one discussing the autopsy report and answering related questions. The same applies for the obstetrician in the case of stillbirth, miscarriage or even early neonatal death. Finding out how the grieving process is progressing and giving parents insight into its natural progression should be a part of this follow-up visit. Paediatricians can help parents understand how to talk to siblings, depending on each child's developmental age.

It is helpful to know the names of regional counsellors and support groups with an interest in perinatal bereavement. Hospital paediatric and neonatal social workers may be a great resource for this kind of information. The role of the paediatrician, the family doctor or obstetrician may be particularly important for monitoring bereaved parent's long term grief resolution, and for determining any degree of pathological grieving, including marital stress and substance abuse. Most perinatal centres have some kind of bereavement support, and community centres or physicians should feel free to take advantage of those services.

Summary

Guiding parents through a perinatal loss is an essential part of caring and contributes to a normal grieving process. The role of the caregiver extends far beyond covering the physiological needs of the infant and starts at the first contact. By creating an atmosphere of trust between parents and caregivers, and a sense of attachment and bonding with the baby, a partnership will be formed between parents and caregivers, which should result in the most appropriate recommendations and decisions for that particular family.

When giving bad news, both parents or one parent with another support person should be present. Simple language should be used, allowing time for listening and answering questions honestly. The best ways that a health care professional can support a grieving family are by offering a nonjudgmental, deep sense of caring and personal involvement. Before and after the death of a baby, parents should be allowed to spend as much time as is needed with their child. Health care staff has to create mementos that will serve as memories later on. Spiritual support should be made available, and the parents' cultural background should be respected. The latter is particularly important with regard to autopsy arrangements. Follow-up meetings to discuss autopsy results or to address unanswered questions also allow evaluation of and counselling for any type of pathological grieving process.

All of the interactions need to take place in a quiet and relaxed environment, while avoiding feelings of pressure or urgency. More practical issues to be considered during and after a perinatal loss are summarized in Tables 2 and 3, and, given minor adjustments, are very similar for all members of obstetrical, paediatric or family care teams. The guidance provided always needs to be individualized, while keeping cultural and religious sensitivities in mind, particularly when the withdrawal of aggressive support is to be discussed. Parents who experience perinatal death under special circumstances, such as stillbirth with or without congenital anomalies or the death of a twin, deserve the same attention and support as those who experience the neonatal death of a singleton.

Caregivers who provide this level of care will fulfill the unique needs of grieving parents by assisting them to have positive memories of their baby, and by giving them a feeling of being cared for in the midst of their pain and grief.

Recommended readings

Church MJ, Chazin H, Ewald F. When a Baby Dies. Oak Brook: The Compassionate Friends Inc, 1981.

Davis DL. Empty Cradle, Broken Heart: Surviving the Death of Your Baby. Golden: Fulcrum Publishing, 1996

Ilse S. Empty Arms: Coping with Miscarriage, Stillbirth and Infant death. Maple Plain: Wintergreen Press, 1996.

Ilse S, Hammer Burns L. Miscarriage: A Shattered Dream. Maple Plain: Wintergreen Press, 1995.

Schwiebert P, Kirk P. When Hello Means Goodbye. A Guide for Parents Whose Child Dies Before Birth, at Birth or Shortly After Birth. Portland: Perinatal Loss Publications, 1998.

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Principal author: John van Aerde MD

References

1. Leon IG. Perinatal loss: A critique of current hospital practices. Clin Pediatr 1992;31:366-74.
2. Chambers HM, Chan FY. Support for women/families after perinatal death (Cochrane Review). In: The Cochrane Library, issue 1. Oxford: Update Software, 1999.
3. Fox R, Pillai M, Porter H, Gill G. The management of late fetal death: A guide to comprehensive care. Br J Obstet Gynaecol 1997;104:4-10.
4. Rando TA. A perspective on loss, grief and mourning. In: Rando TA, ed. Treatment of Complicated Mourning. Champaign: Research Press, 1993:19-77.

5. Kay J, Roman B, Schulte HM. Pregnancy loss and the grief process. In: Woods JR, Woods JLE, eds. *Loss During Pregnancy or in the Newborn Period*. Pitman: Jannetti Publications Inc, 1997:5-36.
6. Parkes CM. *Bereavement: Studies of Grief in Adult Life*, 2nd edn. Madison: International Universities Press, 1987.
7. Ryan R. Loss in the neonatal period: Recommendations for the pediatric health care team. In: Woods JR, Esposito Woods JL, eds. *Loss During Pregnancy or in the Newborn Period: Principles of Care with Clinical Cases and Analyses*. Pitman: Jannetti Publications Inc, 1997:125-57.
8. Kowalski K. Perinatal loss and bereavement. In: Sonstegard L, Kowalski K, Jennings B, eds. *Crisis and Illness in Childbearing (Women's Health)*, vol 3. New York: Grune and Stratton, 1987.
9. Layne LL. Motherhood lost: Cultural dimensions of miscarriage and stillbirth in America. *Women Health* 1990;16:69-98.
10. Rando TA. *Parental Loss of a Child*. Champaign: Research Press, 1986.
11. Rando TA. Risks and therapeutic implications associated with death of a child and AIDS-related death. In: Rando TA, ed. *Treatment of Complicated Mourning*. Champaign: Research Press, 1993:611-50.
12. Rando, TA. *Grieving: How To Go On Living When Someone You Love Dies*. Lexington: Lexington Books, 1988.
13. Fish W. Differences of grief intensity in bereaved parents. In: Rando TA, ed. *Parental Loss of a Child*. Champaign: Research Press, 1986:415-28.
14. DeFrain J, Stinnett N. Building on the inherent strengths of families: A positive approach for family psychologists and counselors. *Top Fam Psychol Couns* 1992;1:15-26.
15. Rando TA. Parental bereavement: An exception to the general conceptualizations of mourning. In: Rando TA, ed. *Parental Loss of a Child*. Champaign: Research Press, 1986:45-58.
16. Finlay I, Dallimore D. Your child is dead. *BMJ* 1991;302:1524-25.
17. Cunningham JH. Spiritual issues and care in perinatal bereavement. In: Woods JR, Woods JLE, eds. *Loss During Pregnancy or in the Newborn Period*. Pitman: Jannetti Publications Inc, 1997:483-98.
18. Luby E. Bereavement and grieving. In: Schiff HS, ed. *The Bereaved Parent*. New York: Penguin Books, 1977:23.
19. Leon IG. Perinatal loss: Choreographing grief on the obstetric unit. *Am J Orthopsychiatry* 1992;62:7-8.
20. Sexton PR, Stephen SB. Postpartum mothers' perceptions of nursing interventions for perinatal grief. *Neonatal Netw* 1991;9:47-51.
21. Bryan EM. Perinatal bereavement after the loss of one twin. *J Perinat Med* 1991;19(Suppl 1):241-45.
22. De Kleine M, Cuisinier M, Kollee L, Bethlehem G, Degrauw K. Guidance after twin and singleton neonatal death. *Arch Dis Child* 1995;36:F125-26.
23. American Academy of Pediatrics. The pediatrician and childhood bereavement. *Pediatrics* 2000;105:445-7.
24. White-Van Mourik MC, Connor JM, Ferguson-Smith MA. Patient care before and after termination of pregnancy for neural tube defects. *Prenat Diagn* 1990;10:497-505.
25. Seller M, Barnes C, Ross S, Barby T, Cowmeadow P. Grief and mid-trimester fetal loss. *Prenat Diagn* 1993;13:341-8.
26. Black RB. A one- and six-month follow-up of prenatal diagnosis patients who lost pregnancies. *Prenat Diagn* 1989;9:795-804.
27. Black RB. Psychosocial issues in reproductive genetic testing and pregnancy loss. *Fetal Diagn Ther* 1993;(Suppl 1):164-73.
28. Baram DA. Termination of pregnancy for fetal anomalies. In: Woods JR, Woods JLE, eds. *Loss During Pregnancy or in the Newborn Period*. Pitman: Jannetti Publications Inc, 1997:307-30.
29. American Academy of Pediatrics and the American College of Obstetrics Perinatal Care. Neonatal special concerns. In: *AAP/ACOG Guidelines for Perinatal Care*, 4th edn. Elk Grove Village: American Academy of Pediatrics, 1997:183-206.

30. Lawson LV. Culturally sensitive support for grieving parents. *MCN Am J Matern Child Nurs* 1990;15:76-79.
 31. Kumar P, Angst DB, Taxy J, Mangurten HH. Neonatal autopsies:A 10-year experience. *Arch Pediatr Adolesc Med* 2000;154:38-42.
 32. Leoni LC. The nurse's role: Care of patients after pregnancy loss. In: Woods JR, Woods JLE, eds. *Loss During Pregnancy or in the Newborn Period*. Pitman: Jannetti Publications Inc, 1997;361-86.
 33. Swanson KM. Empirical development of a middle range theory for caring. *Nurs Res* 1991;40:161-6.
 34. Welch ID. Miscarriage, stillbirth, or newborn death: Starting a healthy grieving process. *Neonatal Netw* 1991;9:53-7.
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Disclaimer: The recommendations in this position statement do not indicate an exclusive course of treatment or procedure to be followed. Variations, taking into account individual circumstances, may be appropriate. Internet addresses are current at time of publication.

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