

Family-Centred Maternity and Newborn Care:
National Guidelines

— CHAPTER 8 —

Loss and Grief

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Introduction

Supporting families through their loss and grief is an integral part of family-centred maternity and newborn care. Maternal and newborn units therefore need to incorporate a system of caring for loss at any time along the maternity continuum.

Each year in Canada, a significant proportion of the babies conceived will not survive. By way of definition, perinatal loss is associated with miscarriage, neonatal death, stillbirth, and therapeutic abortion. (See Glossary in Appendix 7.) Loss, and hence grief, may also coincide with the birth of a preterm infant, an infant who has suffered complications, or an infant with congenital anomalies. It may occur, too, within a family who is giving up a child for adoption (Panuthos and Romeo, 1984).

The emotional impact of perinatal loss is felt by parents, family, friends, and the health care providers caring for the woman and family. Frequently, parents and families will not have experienced a death in the family and are unfamiliar with the grieving process. In addition, many societies view death before birth as a non-event, placing less significance on perinatal death than on the death of an older child or an adult (Brown, 1991).

Grief is the normal, healthy, healing, and loving response to the devastation of losing a loved one. Grief is not an illness, or something to be cured or taken away. Good grief entails remembering and “reliving” — a notion that challenges the unthinking advice often given to parents who have lost a child, such as “keep busy”; “you are young, you can have another”; “you have others”; or “it’s all for the best.” Appropriate support for the grieving process assists families in acknowledging the profound impact of their loss and integrating that loss into their daily lives. It is misleading to think of grief as a static “condition” to be resolved. Grief must be viewed as a process — affected by many influences, including any previous (or subsequent) experience that the bereaved may have had with loss.

Each parent has a unique way of grieving. Consistent with the principles of family-centred care, the role of health care providers and institutions is to support grieving parents and families and to enable them to experience the rituals that are important to them. The families need to be fully and accurately informed about the choices at hand. Institutional

practices, protocols, and belief systems can be helpful, unhelpful, or positively harmful to families at a time when what they most need is understanding, compassion and a sense of control at this time of their lives.

At times, regionalization of maternal and newborn care has resulted in the concentration, in certain centres, of families who are experiencing loss. For centres where that is the case, the incongruity of the co-occurrence of birth and death requires special preparation on the part of caregivers, as well as development of special resources for grieving parents and their families. Many professionals work with individuals or families who have experienced a perinatal loss. These include spiritual advisors, social workers, nurses (hospital and community), clinical nurse specialists, midwives, physicians, psychologists, and other bereaved parents. It is important that representatives of these disciplines work together as an interdisciplinary team. Communication is critical in each situation so that confusion can be minimized and care optimized. Families experiencing perinatal loss will benefit greatly from the establishment of a Perinatal Loss Review Team, comprising representatives from the community-based bereavement support group, pastoral care, the maternal and newborn nursing and medical divisions, public health nursing, and social work. Others, such as local funeral directors and coroner representatives, may be involved as necessary. Regular meetings of this team to consider the parent's experiences, as well as the hospital practices and facilities relating to perinatal loss, will facilitate development of family-centred care.

After a perinatal loss, parents will have choices to make, wishes to express, and expectations to meet. Health care providers must find ways to fulfil these expectations and to make this a positive experience that promotes the well-being of the entire family. In order to achieve this, some institutions have established a Bill of Rights for Parents and Infants. Tables 8.1 and 8.2 present examples of these rights.

Table 8.1 Rights of the Infant

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- To be acknowledged by name and sex
 - To be treated with respect and dignity
 - To be with the grieving family whenever possible
 - To be recognized as a person who has lived and who has died
 - To be remembered with specific mementos (footprints, hand prints, pictures, clothes, name band, ultrasound picture)
 - To be nurtured (wrapped, dressed, cleaned)
 - To be buried/cremated
 - To be remembered
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Source: Women's College Hospital. *Rights of the infant at the hospital: At the time of death*. Toronto: Women's College Hospital, 1984. ©Women's College Hospital

Table 8.2 Rights of the Parent

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- To see, to touch, to hold, to nurture their child with no limitation as to time or frequency
 - To be fully informed about the baby, the cause of death, and the process of legitimizing the death (i.e. the funeral)
 - To have written and verbal information about:
 - the choices available for the burial or funeral
 - the supports available to family members, and
 - the necessary legal information (e.g. timing of burial, birth registration)
 - To receive mementos of their baby (e.g. footprints, picture, certificate of life)
 - To acknowledge the life and death of their child — a person in a family
 - To choose any type of burial, cremation, or other funeral service
 - To be heard and listened to by caring professionals, without judgment or prejudice
 - To have staff who are empathetic, caring, and sensitive to individual responses, behaviour, and choices
 - To be treated with respect and dignity
 - To have family and/or friend support at any time — if the parent wishes
 - To seek religious or cultural support for their choices and to be treated with cultural and religious sensitivity
 - To be aware of the grieving process — to be able to grieve openly or quietly and to be informed of, and understand, the feelings and emotions generated by loss
 - To understand their future options regarding autopsy and genetic counselling
 - To be informed about parent support groups
 - To receive follow-up supportive care (at the hospital, primary care practitioner's office, and/or home) by telephone or by visit
 - To have an opportunity to evaluate their hospital and community experience
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Source: Women's College Hospital. *Rights of parents at the hospital: At the time of the baby's death*. Toronto: Women's College Hospital, 1984. ©Women's College Hospital

Types of Perinatal Loss

Perinatal and childbearing losses take several forms. For the parents, the event precipitates a crisis. Most have been joyfully anticipating a healthy pregnancy; the birth of a healthy child; and a long, healthy life for their newborn baby. They are now forced to cope — perhaps for the first time — with intense feelings of loss. They may have few family members or friends as support through this traumatic event. Indeed, for some, it may be another in a long series of losses. Others may have had ambivalent feelings about the pregnancy and may now feel guilty.

Miscarriages are probably the least acknowledged and most misunderstood of all pregnancy-related deaths; yet it is estimated that they end as many as one third of all pregnancies. Miscarriages can elicit feelings of failure, guilt, or responsibility for the loss; a loss of faith in one's physical body; and conflicts in marriage and family relationships (Panuthos and Romeo, 1984).

Sometimes parents experiencing a *stillbirth* may be unaware that their baby has died and will continue the labour normally, still expecting a healthy baby. Other parents realize that their unborn baby has died. In many cases, the cause of stillbirth is unknown, and the parents will constantly wonder what caused the death. Emotions such as guilt and depression can result from both known and unknown diagnoses (Panuthos and Romeo, 1984).

There are many causes of *neonatal death*. Some babies may be born ill, live a short time, and then die; others may die unexpectedly, as happens with SIDS (sudden infant death syndrome).

Women who decide to have a *therapeutic abortion* have made an informed, but difficult, choice — one based on their life circumstances, their own health, and the potential health of the baby. They may or may not be supported by family and friends in their decision, and may feel they cannot share their feelings of loss.

A *preterm birth*, particularly when the infant has a life-threatening illness, is often associated with anticipatory grief and fear of future developmental difficulties; but there is also hope for survival. When the infant's survival is tenuous and prolonged, eventually resulting in death, parental grief and anguish may be extreme and the stresses on the staff profound.

The birth of a *child with a congenital anomaly* is another type of perinatal loss. With today's better fetal assessment techniques, more parents are prepared for the birth of a baby with anomalies. However, many parents will still be shocked and surprised at the unexpected chronic sorrow that can result from giving birth to an infant who is unable to become their "wished for child." In addition, some of these anomalies may be life-threatening.

Women who give up their baby for *adoption* experience a unique type of perinatal loss. Often, they are unsupported by the child's father, family, and friends. These women experience the usual physical and emotional postpartum changes; however, because these may be unacknowledged or unsupported by others, they may have to suffer their loss in silence (Panuthos and Romeo, 1984).

Assessment

Health care providers have a major role to play in assessing the family's grief reaction, in determining the amount and kind of support needed, and in providing that care and support. An ongoing process of assessment is carried out to ensure that the care and support offered, in both hospital and community, is appropriate. Although not all families will want or require the assistance of a health care provider, these individuals can be valuable allies to the grieving family and help provide appropriate support, referrals, and information.

Assessment of the meaning of the loss precedes planning for support systems and resources. This means exploring, separately, what the loss means to the woman and her partner; to the parents as a couple; and to family and friends. The woman and her partner may lose the image of themselves as parents. The woman herself may suffer loss of self-esteem, while her partner may feel he has lost his role as "protector" and "provider"; together, they may feel they have lost a dream. This is often the first time a couple will have had to face a major crisis, and they may be surprised to find differences in their grief and coping styles. Nonetheless, without this understanding of meaning, future plans and discussions are likely to be inappropriate and even detrimental to the healing process of grief (Kubler-Ross, 1972).

The *process of grieving* has been described in several ways. Most experts, though, describe it as a *process*, with phases or tasks. Identifying this process may help parents who are grieving a perinatal loss. Worden (1991) outlines the tasks of grieving (see Table 8.3). These tasks are not clearly separated; nor are they always sequential or experienced at a particular rate or in the same way (Kubler-Ross, 1972). In effect, there is no one “right way” to mourn, and individual expressions of grief are not “wrong.”

Table 8.3 Worden’s Tasks of Grieving

- Task 1: To accept the reality of the loss.** Even when death is expected, there is always a sense that it hasn’t happened. The first task of grieving is to face the reality that the person is dead.
- Task 2: To work through the pain of grief.** It is necessary to acknowledge and work through the pain or it will manifest itself through other symptoms. This may be difficult if the people around the parents feel uncomfortable with their feelings, and give them the message that their grief is unnecessary.
- Task 3: To adjust to an environment in which the child is missing.** The parents need to search for meaning to the loss in order to make sense of it.
- Task 4: To emotionally relocate the child and move on with life.** This task does not mean giving up their relationship with their child. Instead, it means finding an appropriate place for the child in their emotional lives — a place that will enable them to go on living effectively in the world. The task is to develop some sort of ongoing relationship with the thoughts and memories associated with the child, but to do this in a way that allows them to continue on with their lives after the loss.

Adapted from: Worden JW. *Grief counselling and grief therapy. A handbook for the mental health practitioner*. 2nd ed. New York: Springer Publishing Company, 1991. Used by permission of Springer Publishing Company Inc.

The various elements of grief and loss assessment are presented in Table 8.4.

Table 8.4 Elements of Grief and Loss Assessment

The **sociocultural assessment** addresses factors such as:

- the mother's/father's past experience and customary way of dealing with death or other crisis situations;
 - the cultural or religious practices that the parents may wish to honour or that may constrain them;
 - the past perinatal losses and other losses that may influence the grieving process;
 - the relationship between the woman and her partner, her children, and the grandparents (and the involvement the parents wish the latter to have in the grieving process);
 - the family's support system; and
 - the ages of the siblings and how the parents plan to explain the death to them.
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The **psychological assessment**:

- helps to determine where the family and woman are at in their grieving process; and
 - can use Worden's tasks of mourning as a framework to help families and supporters accept their feelings, understand the importance of expressing these feelings, and gain hope that the pain will diminish.
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The **physical assessment** focuses on:

- the physical effects of pregnancy, labour, and birth and the state of the mother's health during the early postpartum period (this might include such aspects as excessive bleeding or cramping following a D+C, exhaustion following a long and difficult labour, pain following a cesarean section, and breast milk production);
 - the drugs that a woman may have been given that might dull her perception of events and limit her ability to recall the details of her loss; and
 - recognition of any health problems that might affect the mother's ability to conceive and bear children in the future (Kubler-Ross, 1972).
-

The **spiritual assessment** may be overlooked, especially if the woman and her partner do not profess affiliation with an "official" group. However, the spiritual nature of a person is broader than organized religions: all persons have a spiritual self whose needs are likely to be heightened at the time of perinatal loss. It is thus vital to determine:

- what it is that gives meaning to life for the woman and her partner;
 - the kind of faith held by the woman and her partner, and the strength of this faith;
 - if their faith is part of an official religious affiliation — what special rites are necessary to fulfil the beliefs of this religion;
 - what meaning the parents place on this loss; and
 - to what factors they attribute the death.
-

Facilitating and Supporting Grieving

Five Cs have been deemed necessary when providing sensitive support to grieving families: *comfort, caring, communication, compassion* and *continuity* (Jumenez, 1982). A number of other aspects of caring are considered to be important as well. Leon (1992a) summarizes them as the ability to:

- understand the personal meanings of the loss;
- be accepting of the parents' feelings;
- offer realistic support, nurturing, and protection;
- facilitate the expression of grief; and
- help maintain the family's faith in their capacity to come through their loss as functioning, whole people.

When supports and interventions are discussed and planned, the goals of care should be to promote not only personal choice and the decisions made, but also the dignity of (and respect for) the baby, parents, and family. The role of health care providers is to enable parents to do “what they need to do” at the time of death.

Interventions for supporting loss and grief have been classified as supportive, informational, and facilitative (Brown, 1991). They are outlined in Table 8.5.

Table 8.5 Interventions for Supporting Grief

Supportive interventions focus on reassuring parents that their expressions of grief are encouraged and accepted — no matter the form. Health care providers also need to take the time just to “be” with grieving parents. Grieving parents will likely want privacy, but they should not be abandoned or ignored.

Informational interventions include providing information about grief and what parents can expect in terms of their own responses. Parents need to know that their reactions are normal, that there is no timetable for grieving. Couples and families need to know that men and women grieve differently. Other interventions entail verbal and printed information about burial and cremation procedures, memorial services, legal requirements, hospital regulations, and community services including bereaved parent support groups.

Facilitative interventions are directed at making the loss real, coordinating care, helping families navigate the legal requirements, and helping them prepare for the future. Activities such as filling out the necessary forms, contacting a chaplain or funeral director, or “running interference” for the client can all be supportive roles for health care providers.

Supporting the Family

It is crucial to keep parents informed throughout the loss experience. It is also critical that the mother's main support person remain with her. As well, parents may wish to have an identified hospital staff member or a member of a perinatal support group with them for support.

If at all possible, an explanation of the birth and the circumstances surrounding the death should be provided to parents when they are together. Writing down the information for them and encouraging them to draw up their own questions for clarification is sometimes helpful. Providing privacy for a family who would like to be with their baby at the time of death, and afterwards, can be an important intervention. A quiet, if at all possible, private room that is part of the maternal and newborn unit should be made available. Overnight accommodation, if available, should be provided for the mother's partner or another supportive person.

A mother needs the option of staying in the maternal and newborn area or being transferred to another area of the hospital, where the staff are skilled in caring for families experiencing perinatal loss. She should not be expected to share a room with another mother and baby.

It is often helpful for parents to see their infant; the decision, however, is up to the parents. Some parents may want to bathe and dress the baby themselves. Parents often say that it is important to see the baby's entire body — that it reinforces the idea that their baby was indeed a real little person who lived and died. Some parents may wish to provide special clothing, blankets, or toys for their child. Siblings may wish to contribute poems, letters, artwork, or toys as an expression of affection. Whereas physical contact with the dead child is often a valuable way of expressing grief, it is not the only outlet; nor is it optimal for all parents. Parents who decide not to view the dead baby are not necessarily in danger of complicating their grief process. No parent needs to foster a burden of guilt.

Parents may need time to reconsider their initial decision not to see the baby. There is no rush. Other parents may wish to see their baby several times before leaving the hospital. Likewise, parents may want their relatives to see and hold the baby.

Parents should be offered photographs and other mementos of the baby (see Table 8.6). They may also wish to take photographs themselves. Parents may not want the photographs at this time, but they should be kept on file in case the parents change their minds. Written information on how

to access the photographs at a later date should be given to the parents. If it is culturally appropriate, parents can be encouraged to give the baby a name.

Health care providers can facilitate an initial contact between the grieving parents and parents who have experienced a similar loss. If the parents wish, a member of a parent support group can be asked to come to the hospital. If the parents do not feel ready for such contact, written information can be provided. The family is then free to contact the support group at a later date.

Communication

Health care providers can play a major role in supporting partners — allowing them to talk about their feelings, or to express their feelings in a way that is appropriate for *them* (e.g. by writing or drawing). In fact, parents should be encouraged to communicate with each other, to share their feelings, and, if possible, to talk about their loss. These feelings often include anger; health care providers must be prepared for this reaction and accept it. Stress on the family, and the relationship, is a major factor to consider when caring for the family. As already mentioned, men and women often react to loss and experience their grief quite differently. Because the mother physically carries the baby, she experiences a unique physical and emotional relationship with the unborn baby.

If there are other children in the family, the parents will need to consider how and what to tell them. Health care providers can help the parents decide how to share the information. The best practice is to be open and honest. Children need clear reasons about how and why the baby died so they do not invent their own reasons. It is important to explain that the baby has *died*; they should not be told that the baby has simply “gone to sleep” or been “lost.” Otherwise, children may worry about their own safety or wonder if mum and dad will also get “lost” or “go to sleep.”

Some parents may be unable to express their feelings at the time of their loss. Indeed, it may be some time before they can share their feelings, even with close family members or a partner.

Parents will need help in preparing for the reactions of family, friends, and the community. A discussion of potential responses and ideas may be of use. Sometimes comments, though well meaning, can be hurtful; parents need to be prepared for this. It is also helpful to have the parents identify

what assistance would be useful at home (e.g. help with meals, housework, and the care of other children). Parents need to understand too that, because of their trauma, they should not be too hard on themselves. They cannot expect to cope with as much responsibility as was possible before their loss.

Active listening is particularly important when working with grieving families. Health care providers need to focus on what the parents are actually saying and not on what they (the providers) think they should be saying. The danger lies in pushing parents to make decisions quickly and not paying attention to their real emotional needs and the expression of these needs. It is often necessary to repeat information. Families may find it difficult to understand and make use of the information provided. But there is no rush. The crux of the matter is that the parents need time to make informed decisions.

Cremation, Burial, and Funeral Options

Parents will need explanations about cremation, burial, and funeral options, as well as autopsies and the necessary legal documents. They may require assistance to reach decisions and complete the necessary documentation. (See section on Laws in this Chapter, p. 19.) It is important to encourage both parents to become involved in the burial plans and to offer assistance in making the arrangements; this may include finding out about local funeral homes. The parents' relatives may be particularly helpful with this aspect of care; it can give them something useful to do at a time when they are feeling helpless.

Remembrances

Parents should be provided with remembrances, including keepsakes, in memory of the baby. These can be given to the parents at the time of the infant's death or at a later date. Examples of possible remembrances are listed in Table 8.6.

Table 8.6 Remembrances

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- Identification bracelet
 - Bassinet card with infant's name, date of birth, date of death, and weight
 - Lasting photos of the infant. If the parents decline the photos, advise them that they will be placed in the hospital record for future pick-up. Some parents will ask for pictures of their baby both dressed and undressed.
 - Photos of the infant with parents and significant others who are present (if the parents desire)
 - Footprints and hand prints on a card
 - Lock of hair, according to the parents' wishes
 - Ultrasound picture
 - Measuring tape
 - Hat and booties, blanket, christening dress, the clothing the baby died in, other clothing
 - Poems, special notes to the family
 - Certificate of death and a photocopy
 - Autopsy results
 - Certificate of life (to be created by the institution)
 - Mementos from the "naming ceremony" (candle and certificate)
 - Any other special items that the family may wish to keep
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Special Considerations for a Woman Who Has Had a Miscarriage

Women experiencing a miscarriage may be admitted to the hospital through their physician's office, via the emergency department, or straight from home. It is crucial that they be treated with sensitivity and that the emotional aspects of their loss, as well as their physical symptoms, be dealt with. Women have often stated that if they come to the emergency department when having a miscarriage, the attending health care providers seem to downplay the event. Clearly, it is imperative in these circumstances that both women and families have appropriate referrals to help them deal with their loss.

Because viewing, holding, and having private time with the baby may be impossible, health care providers should spend time with the parents talking about the baby and the parents' broken hopes and dreams. It is important to encourage the parents to honour their baby in some way; for example, they might name the baby or make a keepsake album with cards and perhaps an ultrasound picture.

Staff members should always use the term "miscarriage." Every effort should be made to avoid the word "abortion," as this may lead to confusion, misunderstanding and unnecessary pain. Recommended terminology

includes such terms as “threat of miscarriage,” “incomplete miscarriage,” or “silent miscarriage,” rather than “missed abortion.”

Whenever possible, a woman experiencing a miscarriage should be offered the option of watchful waiting, a surgical D+C or a medical D+C. Many women understandably fear a surgical D+C for it often involves general anesthetic and further loss of control. When explaining a surgical D+C, staff should note that this procedure helps to bring about closure and may reduce the risk of bleeding and infection. Sometimes women think that a surgical D+C involves scraping the baby out or removing decayed tissue. Perhaps the term “removing any fragments of the placenta” would be more consistent with the goal of “gentle truth telling.”

Sometimes, early pregnancy loss is discovered during an ultrasound. It is important that the woman be informed of the loss clearly at the time of the scan. The physician conducting the ultrasound should tell the woman of the findings and contact her physician as soon as possible, so that ongoing care and support can be coordinated. Providing immediate emotional support is critical and may ease a woman and her partner’s natural reaction to the loss. It is crucial, too, to express sympathy, provide an opportunity to ask questions, and offer a quiet place for initial reflection. It may also be important to reassure the woman that she is not to blame for the miscarriage (Franché et al., 1997). The parents should not be left alone; that is, not sent home alone or sent to the hospital to check in alone. A relative, friend, neighbour, support person, or hospital volunteer should be asked to accompany the parents.

Most women and partners say they need information about the cause of the loss and about any further care required. In general, the woman’s own physician, rather than the ultrasonographic physician, is better placed to provide the detailed information required (Franché et al., 1997).

Special Considerations for Parents of Babies Born Prematurely or with a Congenital Anomaly, and Babies Who Have Suffered Complications

Parents whose babies are born prematurely, suffer complications, or present with congenital anomalies have special needs. Along with the joy of birth and the delight of welcoming a new baby into the family, these parents may experience a sense of loss: the baby is not as they had expected. Health care professionals need to rejoice with the parents in the birth of their baby,

while simultaneously acknowledging and validating their loss and grief. Parents will need to receive as much information as possible regarding their child's condition. Appropriate and supportive community referrals will have to be made by hospital staff. In the end, parents may benefit from the support of other parents whose children have similar anomalies.

Bereavement Guides

It may be useful to use a form that outlines recommended care for bereaved families. Staff members can then offer parents all pertinent, available options and ensure that the appropriate community links are established. Each centre should develop its own tools, thereby developing aids specific to the institution and the community. See Appendices 1 to 5 for examples of such forms.

Cautions

Health care providers should remember that grieving is unique to the individual, that it cannot be normalized with rules and regulations as to what parents should or should not do.

“Before grieving can be labelled normal, disturbed, or distorted, there must be an understanding of what the loss means to the bereaved and how their thoughts, feelings, and actions attempt to cope with or avoid that loss. For the caregiver, this understanding means feeling with the bereaved and sharing their pain, without being consumed by its intensity... [it means] offering empathy... We need to distinguish carefully an approach that genuinely promotes empathy from one that is programmed” (Leon 1992b).

The quality of the relationship between the provider and parents is more important than rigidly following a protocol. It is critical that elaborate instructions for caregivers — do's and don'ts of what to say and lists of what needs to be done — should never dictate parent-provider interactions. Applying protocols rigidly may derail the caregivers' empathy, leaving the bereaved parents even more bereft.

Religious and Cultural Diversity

Canada is a multicultural nation. Each culture and religion has its own beliefs and customs surrounding death, cremation, burial, the roles of family members, and the grieving process. Additional norms may also exist with regard to how different cultures and religions view perinatal death.

Health care providers must therefore explore the specific beliefs and wishes of parents; they must honour these differences and provide every opportunity for parents to exercise their choices. Health care providers may find it useful to consult local religious advisors for guidance. Of course, a parent may be part of a certain culture or religion and yet not adhere to all of the beliefs and customs of that particular group. The following examples illustrate various differing cultural norms. Some religions and cultures:

- require burial within 24 hours of death, while others will wait for a number of days;
- do not consider cremation as a legitimate way to dispose of a body;
- choose to have the placenta buried with the child, while others may wish to bury it separately. Some parents bury the placenta even though the child lives;
- will not permit the child to be named if the death is a result of miscarriage or stillbirth. Some faiths do not name, or have funeral rituals for, babies who have lived less than a certain number of days;
- require the mother to remain isolated from all friends and to stay at home for a specified period of time; and
- encourage loud wailing to demonstrate the parents' loss, while parents from other cultures are seemingly non-demonstrative and display little emotion in public.

Laws

Postmortems

Each province or territory is unique. It is therefore the responsibility of the health care provider to be knowledgeable about, and inform the parents of, the provincial or territorial laws regarding postmortems. In some provinces and territories, a postmortem may be required by law. In others, it is the parents' choice. In addition, some religions will not permit a postmortem.

Burial and Cremation

Provinces and territories differ when it comes to cremation, burial, and tissue disposal regulations. Health care providers need to familiarize themselves with the regulations in their province or territory. This information should be made available at the hospital unit. Professionals need to discuss the options regarding burial, cremation, and disposal of remains *regardless of the baby's gestation and weight*.

When arranging burials, cremations, or other memorial ceremonies, health care professionals should consider the following factors:

- Funeral services and burials are an individual choice, based on preference, tradition, culture, and religion.
- Parents may choose to have the baby share the family burial area.
- Individual and family preferences, as well as cultural beliefs and customs, may differ from the norms prescribed by institutional guidelines.

Funeral homes are showing signs of increased understanding — not only of infant deaths but of the resulting needs of parents, siblings, and extended family and friends. In addition, they are becoming more sensitive to the needs for services for babies weighing less than 500 grams and who are less than 20 weeks' gestation. It might be helpful to include funeral directors when discussing or planning programs, or educating staff.

Transportation

Some parents may wish to have a funeral home transport their baby from hospital to funeral home. Others will insist that the child leaves the hospital with the mother. Some parents may wish to place the infant in the coffin before the baby leaves the hospital. A small white box, or a similar container, will be required to transport the child to the funeral home of choice. Some hospitals provide these boxes, appropriately decorated; in other instances, the parents may have to provide them. The funeral home must be contacted prior to the transport.

Some parents who live a great distance from the hospital have requested that they, or a close relative, transport the deceased baby in a family car to the local funeral home. In this instance, a hospital policy and written consent form are required, transferring responsibility to the parents. Lawyers may need to be consulted to facilitate this process. The health care

institution should provide the parents with burial and transportation guidelines.

Returning to Work

The laws concerning return to work after a perinatal loss vary by province or territory. In most provinces and territories, the normal number of weeks of employment insurance awarded for postpartum leave is not provided for parents experiencing a loss. As well, the leave available to women who have suffered a perinatal loss varies by individual employer, union standards, and company policies.

Employers must be sensitive to each woman's individual need for enough time to physically and emotionally begin the grieving process. Sufficient time is also required for the pregnancy hormonal levels to return to normal. For most women, the usual three-day bereavement leave is inadequate to absorb the impact of such a loss. The father may also need to be with the mother, to initiate his own grief process. Health care providers may need to provide medical certification so that the woman does not have to return to work too early. On the other hand, some women may choose to return to work earlier than others; these women should be supported in their decision.

Program staff should educate the community about the needs of parents who have experienced a perinatal loss. Depending on the individual situation, parents who experience a perinatal loss may require anywhere from six to eight weeks of bereavement leave.

Educating and Supporting Staff

Ideally, all health care providers will have received an academic grounding and clinical experience in how to support individuals through the grieving process. All training programs should cover basic information on the grieving process and the role of the health care provider in supporting individuals and families.

All staff working on neonatal intensive care units, maternal and newborn units, and pediatric units as well as in emergency rooms and recovery rooms need specific instructions on ways of supporting and assisting parents who are grieving a perinatal loss. Discussions on these

matters should be incorporated into their orientation and continue, at regular intervals, during the course of employment. As well, in-service modules should be developed to deal with professional care issues concerning grieving and the health care provider's role.

Orientation and in-service education programs should focus on the following issues:

- the principles of family-centred care and working with families;
- the positive components of working with death and dying;
- the different types of perinatal loss and the potential support roles for health care providers;
- the parents' and sibling's experiences of perinatal loss;
- the parents' feedback on support provided during the grieving period;
- various practical strategies for helping parents; and
- the diverse community resources available to parents, including parent support groups.

Health care institutions and agencies should be encouraged to provide forums at regular intervals that allow for staff discussion of issues regarding the care of mothers and parents who have undergone a perinatal loss. Rounds, workshops, and discussion groups are among the possible venues.

Health care providers who support parents through the grieving process will often require support themselves. Ways of providing such support include:

- Create opportunities for health care providers to get together as a group to discuss individual situations, as well as their own feelings and needs.
- Offer staff members suggestions as to what to say in situations of loss.
- Provide a quiet room for staff use.
- Put on extra staff when a death occurs — often, two nurses are needed.
- Ensure that staff members have sufficient time to spend with the families.
- Identify the rooms of families who have suffered a loss, so that all staff members know that a family is grieving before they enter the room. For example, place a butterfly over the doors of these rooms.
- Pair experienced staff with new staff members so they can give guidance.
- Provide staff members with opportunities to communicate with and support each other, through support groups.
- Offer staff members Employee Assistance Programs (EAP).

Above all, it is critical that all health care professionals respect each other's feelings.

Facilitating and Supporting Grieving in the Community

When a family experiences a perinatal loss, its members need access to supports and referrals in the community. Because the loss usually occurs in a hospital, the woman or couple may well return home without the necessary support. It is up to the hospital and community health care providers to ensure that families receive follow-up and appropriate support services — all with informed consent. Depending on the size and nature of the community, support resources may include parents or grandparents, close friends, a self-help group, and/or professionals.

Collaboration between hospitals and community health agencies is needed to determine what resources are available in the community and how to make the appropriate referrals. Community support of parents experiencing perinatal loss is best given by a team. Team members might include family members, nurses, social workers, friends, physicians, clergy, funeral directors, bereavement counsellors, and parents who have experienced a perinatal loss. The family physician or midwife and community health nurses are particularly significant members of this follow-up team.

Follow-up care includes assessing the status of the grieving process, offering continued support, validating the cause of death when autopsy reports are made available, and exploring residual doubts and questions. This follow-up needs to be organized and coordinated if it is to succeed. Family needs dictate the follow-up frequency and schedule.

Families that have experienced a perinatal loss will require information regarding bereavement support groups. (See next section, Parent Support Groups). If such a group does not exist, hospitals and/or community-based agencies should consider organizing one. Parents who have had similar experiences can be valuable allies and facilitators in this process.

Some parents may benefit from reading material or educational videos on bereavement. A library of books and videos or an information packet

can be made available for loan or reference at the hospital, home, support group, or local library.

Isolated communities often present special challenges for follow-up. Although many women with complications of pregnancy come from these communities, their health care providers in large urban centres may be unaware of the resources and networks available once the family returns home. Telephone consultations and personal referrals, however, constitute a good first step, inasmuch as distance can delay transmission of written documents or referrals. It is also beneficial to create reference manuals for specific referrals and specific communities. The Internet is now providing excellent resources and links for parents and health care providers living in isolated communities.

Centres can provide annual group memorial services and/or a group burial area to commemorate infant deaths. Parents and health care providers participate in these services, which can be held at the perinatal/pediatric centres, a local cemetery, or elsewhere.

Creating a supportive community for perinatal grieving can also be achieved by increasing public awareness of the perinatal loss experience. Health care providers and parents need to work together to tell the parents' stories.

Parent Support Groups

Families in crisis can turn to community-based support programs for help. There, families experiencing the same issues are encouraged to share their stories and to find strength — within each other and themselves. These programs provide services that effectively complement the health care system. For a bereaved person, these “self-help/mutual aid” programs can be a sanctuary, a source of support and comfort through the intensity of their grief journey.

As the name implies, *self-help* support programs are useful for individuals and families *who have the potential to help themselves*. A self-help program provides an accepting environment for bereaved individuals to tell their story. There they can remember and talk about the person who has died; they can be supported through the normal process of grieving; and they can express the normal range of emotions and response — the anger,

confusion, shock, self-blame, depression, and guilt — that accompany grief. Friends and family may consider these feelings unacceptable, uncomfortable, perhaps even unhealthy; within the self-help bereavement community, however, the expression of these feelings is accepted.

Mutual aid is a logical, natural by-product of self-help. In seeking support for themselves, bereaved parents assist other members of their group. The mutual trust within a self-help group allows members to assess their own experience — not only accepting the reality of the loss, but also “normalizing” the roller coaster of feelings associated with their loss. Loss of self-esteem, self-doubt, feelings of guilt and self-reproach — all are frequent complaints of bereaved parents. In consoling other parents, the bereaved learn to value their own strengths and the knowledge gained from their experience. Thus, they begin to restore their own sense of self-worth.

As the focus of the bereaved parents becomes less internal, they increasingly look toward the outside world. The true purpose and success of such “grief work” is to help the bereaved to return eventually to the mainstream of life, to function again in the “outside” world.

Supporting Grieving Families Through Self-Help and Mutual Aid

A community bereavement group can provide grieving families with the requisite safe place and grieving time. Within the self-help/mutual aid setting, group members devote time and energy to sharing their stories and remembering their child. Parents whose baby has died can “check out” the reality of their loss. Sometimes, it may even seem that their baby never existed. In a self-help group, they can identify and validate the source of their pain, thereby allowing the grief to become “real.” Initially, this process may seem to intensify the grief. Yet, the seeming paradox of grief is that in sharing their story, and their child, with an accepting and supportive group, parents begin to assimilate their experience and eventually “move on.”

After the death of a loved one, families may feel pressure to resume their usual schedule, to lead a “normal” life, and, in general, to behave as if they had not suffered a traumatic loss. Often, employment demands lose sight of the bereaved, who may feel unable to return to a job, let alone function at their customary performance level. Well-intentioned family and friends may be unaware and uninitiated in the demands of grief, and offer misguided advice to survivors. In addition, day-to-day demands may leave

parents with little time (or the inclination) to tend to their own needs and grief journey. Sharing individual strategies for coping with the challenges of day-to-day life is part of the agenda of a support group meeting.

These groups are facilitated by parent volunteers. Bereaved parents often have clear insights as to what helps and hinders the healing process of grief. Many, moreover, are able and willing to assist others struggling with this process. In self-help/mutual aid programs, volunteers can comfort and support the bereaved through the normal grieving process. Their experiential knowledge of loss gives credibility to their role within the group.

Self-help/mutual aid does not work for all families. Professional help may be necessary. In the end, the solution may be individual counselling, or professionally run therapy groups staffed by professionals with expertise in bereavement work.

Caregiving Professionals vis-à-vis Self-Help and Mutual Aid Models

Health care providers — therapists, spiritual advisors, nurses, physicians, midwives, social workers, psychologists, and others — can play a vital role in supporting and sustaining self-help/mutual aid services within the community. Caregiving professionals can be involved in many ways:

- After a loss, health care providers can encourage bereaved families to seek the support of people who can assist them in their grief journey.
- Health care providers can also act in an advisory and support capacity to parent volunteers.
- A skilled and knowledgeable health care provider can assist volunteers in defining the limitations of the support provided by a self-help/mutual aid program.
- Health care providers who volunteer within community support organizations can assist bereaved parent volunteers in identifying the newly bereaved who are in need of professional assistance, or perhaps even crisis intervention.

Strategies for Self-Help and Mutual Aid

A variety of strategies can be used to provide support for the bereaved within a community. Factors such as population and proximity to larger centres, as well as cultural considerations, may influence the strategies deployed in a particular community.

One example of a self-help/mutual aid organization that offers bereavement support, and has affiliates throughout the province, is Bereaved Families of Ontario. Its affiliates' programs and strategies are tailored to meet the needs of the specific communities they serve. For example, in major urban areas, the large number of parents seeking support has meant the development of specialized services, such as an infant-loss program. In smaller communities, the lower demand for support services may mean a less specialized type of support.

Bereaved parent groups use the following strategies to develop support programs:

- **Open meetings:** Open meetings occur at regular intervals, with members attending on a regular or sporadic basis. Some open meetings focus on special themes, with guest speakers who have expertise and sensitivity in issues related to grief and loss. Volunteer facilitators with training in group dynamics may assist with the group discussion.
- **Closed support groups:** “Closed” groups have a limited membership and a fixed number of meeting dates. The same members participate in group sessions for the duration of the group. Members of a closed group proceed together, from one meeting to the next, gaining familiarity and trust. Topics for discussion may initially follow an agenda. For example, the first meeting is often devoted to “storytelling,” where each member has the opportunity to share his or her experience of loss with fellow group members. In time, group members will shape the agenda for discussion, as their own interests and needs dictate.

Whether a group is open or closed, *confidentiality is critical to enhancing a trusting relationship among group members*. A group provides a safe place, where the bereaved can be heard, accepted, and supported through the intensity of their grief.

- **One-to-one “buddy” support:** Once parents are matched with others who have experienced a similar loss, their one-on-one interaction

becomes an effective way of providing comfort to families, especially those who are newly bereaved. There are many potential criteria for pairing parents. The actual support can be done face-to-face, by phone or computer link, or by mail.

- **Media and Print Resources:** In recent years, the growth of materials specific to the needs of bereaved people, in both the print and electronic media, has been tremendous. These materials can be valuable resources for any support program. But they are especially helpful when families have little opportunity, or inclination, to interact directly with other bereaved people. The most useful materials engage the readers via the stories of families who have experienced loss. The voice is personal; it assists the bereaved by “normalizing” the grief experience, and helping them to give shape and “language” to their own experiences with loss. (See Appendix 6.)

The growing interest in computers, particularly the Internet, has opened a whole new world of bereavement support that is both widely accessible and economical to use. Many bereaved people actually find it easier to seek support through computer resources, given the measure of privacy and anonymity offered. (See Appendix 6.)

In recent years, several larger, well-known publishing houses have included books on grief and loss issues in their published titles. Many of these are available through mainstream bookstores and public library systems. As well, some speciality booksellers have extensive collections and bibliographies devoted to family issues, including bereavement and grief support. These resources, and others, are outlined in Appendix 6.

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APPENDIX 1

Checklist for the Care of Women Experiencing an Early Pregnancy Loss

This form is to be used for *all* women who experience a pregnancy loss prior to 22 weeks' gestation.

A. INFORMATION

Check those sources of support requested by the women, or identified by the nurse, as being of possible use.

- Why Me?* brochure (routine)
- Miscarriage Support Booklet* (Bereaved Families of Ontario Booklet) (routine)
- Chaplain (Name):
- Social worker (Name):
- Blessing

B. TREATMENT OF FETUS

Fetus identifiable (may or may not be intact) — Determined by: (initials)

- Viewing requested Yes No
- Viewing completed Yes No
- Burial information — Provided by: (initials)
- Burial at hospital cemetery Yes If yes, form completed Yes
or
- Burial by parents/funeral director Yes If yes, form completed Yes
Letter from physician regarding gestational age completed Yes
Record and Notification of Death/Morgue Admission and Discharge form
addressographed and marked "Fetus of" Yes
- Pathology
Detailed pathological exam requested Yes No
If no, Regular Surgical Pathology Requisition completed Yes
If yes, consent form completed Yes
Pathological Requisition, including gestation data completed Yes
Fetus in formalin sent to Pathology (in same or separate container
as placenta) Yes — Sent by: (initials)

Fetus unidentifiable — Determined by: (initials)

- Pathology
Fetus in formalin sent to Pathology (in same or separate container
as placenta) Yes — Sent by: (initials)
Accompanied by: regular surgical pathology requisition Yes
If family wishes to bury "unidentifiable fetus," follow protocol under
"Fetus identifiable" and under "Burial by parents/funeral director."

C. GRIEVING PROCESS

Discussion of grieving process initiated by: (initials)

Physician Follow-Up — Name:

Comments:

.....

.....

APPENDIX 2

Interdepartmental Perinatal Loss Flowsheet

Use this Perinatal Loss Flowsheet to facilitate communication, avoid duplication and provide guidelines for all staff. Initiate steps outlined in Perinatal Loss Flowsheet as soon as pending/actual loss is identified.

Signature	Initials
Signature	Initials
Signature	Initials
Signature	Initials
Signature	Initials
Signature	Initials

ACTIONS

1. Notify Social Work Department

Name of Worker:

Interpreter needed: Yes No

Name: Phone Number:

<i>Action taken?</i> <input type="checkbox"/> Yes <input type="checkbox"/> No	Date	Initials
---	------------	----------------

Patient wishes to see Patient does not wish to see

Comments:

2. Notify Pastoral Care Department

Name of Chaplain:

<i>Action taken?</i> <input type="checkbox"/> Yes <input type="checkbox"/> No	Date	Initials
---	------------	----------------

Patient wishes to see Patient does not wish to see

Comments:

3. Birth Unit notifies Admitting Unit by phone when stillbirth occurs.

Primary nurse, social worker, or chaplain will provide family with Perinatal Loss Package. Social worker or chaplain will add information based on individual need.

<i>Action taken?</i> <input type="checkbox"/> Yes <input type="checkbox"/> No	Date	Initials
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4. Explore naming the baby.

Ask: "Have you thought of a name for your baby?"

Action taken? Yes No Date Initials

Name:

5. Explain butterfly and place on door/isolette.

Action taken? Yes No Date Initials

6. Identify whether parents would like to:

- a) see baby Yes No Undecided
 b) hold baby Yes No Undecided
 c) other (dress, bathe, etc.) Yes No Undecided

Specify:

.....

Action taken? Yes No Date Initials

7. Explore family's cultural/religious beliefs.

- a) Blessing (for stillbirth) Yes No Date

Denomination:

By:

- b) Baptism (done for live birth celebration) Yes No Date

By:

- c) Memorial service — other Yes No Date

Identify:

By:

Family's clergy notified Yes No

Name:

- d) Other options:

.....

Comments:

.....

Action taken? Yes No Date Initials

8. Provide a picture of the baby.

Say: "We will take a Polaroid picture of your baby. Many parents like such a picture for a keepsake." (If parents are undecided, attach the picture to the mother's chart, in a small brown envelope.) The social worker/chaplain can encourage the family to take the picture home and keep it in a safe place. If a bonnet is used, place it in a plastic bag and send it with the mother's chart. Washing of bonnet will be done as requested. A photocopy of the Polaroid picture ensures it will last. Encourage families to bring in their own cameras.

Yes No Undecided

- Picture: Given to mother
 On mother's chart
 Sent to social work department on discharge

Action taken? Yes No Date Initials

9. Provide information on autopsy.

Say: "Everyone wonders why a baby dies. Sometimes an autopsy will help us find some answers. Would you agree to an autopsy?" Note that a preliminary autopsy report takes four to six weeks or longer while a final autopsy takes three months or longer.

- Yes No Undecided

Ask, "Will other close relatives/friends wish to see the baby?"

- All viewing completed: Yes No

Remember that until all viewing is completed, the *autopsy consent form* remains with the other death documentation forms in the Death Documentation Envelope on the chart. Once these forms are sent to the Admitting Unit, viewing of infant is no longer recommended.

Autopsy consent form sent to Admitting Unit with other completed forms:

- Yes No

The autopsy must be completed within 12 to 24 hours after birth.

Action taken? Yes No Date Initials

10. Provide accommodation

Mother will be accommodated in a private room on the mother/baby unit. A sleep chair is provided for the support person. Although they will see and hear babies, they will receive support from staff. If no private room is available, the mother should stay in a semiprivate room, with the other bed used by the support person.

Room #

- Support Person staying: Yes No

11. Provide family with remembrances.

Check off those given.

- Bonnet
- Lock of hair
- Photo
- Crib card
- ID band
- Addressograph
- Butterfly
- Clothing
- Other:

Action taken? Yes No Date Initials

APPENDIX 3

Step Checklist

1. Infant taken to morgue, in container provided by morgue (kept in birth area).
2. Forms sent with infant to morgue.
3. Autopsy initiated, after all remaining forms in Death Documentation Envelope have been received by Admitting Unit.
4. On receipt of all forms, the admitting department:
 - i) contacts the morgue
 - ii) releases the body to the funeral director, once the morgue has confirmed that all procedures are completed and the social worker or chaplain has confirmed the name of the funeral home chosen by parent(s).
5. Funeral decisions made. Parents are responsible for the burial of all babies greater or equal to 22 weeks' gestation. It is not necessary to make any immediate decisions. Members of the following disciplines can discuss burial: pastoral care or social work (or nursing if pastoral care or social work staff are unavailable). Parents should be asked: "Have you thought about burial/funeral arrangements?" It should be suggested that they or a family member contact the funeral director of their choice. The service can be delayed until the mother can be present.
 - a) Other sources of support discussed, and notification ensured or information made available prior to discharge.
 - b) Pamphlets on parent groups for bereaved families made available in Perinatal Loss Package.
 - c) Referral made to public health.

Only the social worker or chaplain should notify the Admitting Unit when all viewing is completed, and the name of a funeral home has been chosen by parent(s).

Admitting notified by: Date

Funeral home being used:

Family physician Name:

Referral form completed: Yes No

6. All necessary documentation completed (as per policy/procedure manual).
Once viewing is completed, the primary nurse ensures that all completed forms are placed in the Infant Death Documentation Envelope. Envelope is sent to Admitting Unit by a porter (do not place in mail system).
7. Classification of event (miscarriage, abortion, stillbirth, neonatal death) made by obstetrician or attending family physician at the time of the event.

Date Sent: Initials:

APPENDIX 4

NICU Bereavement Checklist

Baby's name:

Mother's name Father's name

Date of birth: Hospital no.:

Address:

Siblings + Ages:

.....

.....

Current Loss:

Stillbirth Live birth

Sex: male female Weight Gestation

Previous loss:

Miscarriage Live birth Stillbirth Infertility

INDICATE COMPLETION	DATE	TIME	SIGNATURE
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Mother and father saw baby when born and/or after birth: M F

Mother and father held baby after birth: M F

Mother given option of being transferred out of maternity department:

Antepartum Postpartum Gynecology

Pastoral care offered: Y N

If yes, seen by:

Baby baptized: Y N

By:

Date: Time:

Social worker involved:

A picture given to parents: Y N

Kept on file: Y N

Keepsake memories given to parents: Y N

"When Hello Means Goodby"/"Beginnings"

given to parents: Y N

Did parents name baby? Y N

Given Name:

Burial options explained: Y N

Hospital Private

Burial permit (from Admitting) requested, if taking body home

Autopsy desired: Y N

Consent obtained: Y N

Community resources offered: Y N

APPENDIX 5

Follow-up Communication

Follow-up person:

Initial contact Date:

Comments:
.....
.....
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Three months Date:

Comments:
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.....
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Six months Date:

Comments:
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One year Date:

Comments:
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Additional comments:
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APPENDIX 6

Further Reading

BOOKS

Parents and Health Workers

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"A Child's Grief," 1994, 54 minutes (video)

Available through Magic Lantern Communications Ltd.

#38-775 Pacific Road, Oakville, Ontario L6L 6M4

Tel.: (905) 827-1155, 1-800-263-1717 Fax: (905) 827-1154

e-mail: video@magiclantern.ca

ORGANIZATIONS

There are a number of bereavement groups in Canada and the United States. Many of these are community based. Parents should be helped to find the group in their community. The following is a list of some national and provincial organizations.

Bereaved Families of Ontario provides professionals and families with educational workshops for support and training purposes. It also provides self-help, mutual aid, and resources through its affiliates.

562 Eglinton Avenue East, Suite 401, Toronto, Ontario M4P 1P1

Tel.: (416) 440-0290

Fax: (416) 440-0304

e-mail: bfo@inforamp.net

<http://www.inforamp.net/~bfo/>

Canadian Foundation for the Study of Infant Deaths (The) “SIDS Foundation”

586 Eglinton Avenue East, Suite 308, Toronto, Ontario M4P 1P2

Tel.: (416) 488-3260 (toll-free number: 1-800-END-SIDS)

Fax: (416) 488-3864

e-mail: sidscanada@inforamp.net

Compassionate Friends of Canada (The)

Pat Pinch, National Office Secretary

685 William Avenue, Winnipeg, Manitoba R3E 0Z2

Tel.: (204) 787-4896

Fax: (204) 475-6693

e-mail: TCFLAC@aol.com

Pen-Parents of Canada

This organization publishes a small magazine dedicated to providing support to families which have experienced pregnancy and infant loss. A substantial portion of the publication consists of articles and poems submitted by its readers. *Pen-Parents* is available at a nominal cost through subscription order.

Pen-Parents of Canada

PO. Box 32348, RPO Coquitlam Centre, Coquitlam, British Columbia V3B 7Y4

Subsequent Pregnancy After Loss (SPALS)

An on-line discussion group at <http://www.inforamp.net/~bfo/spals/>

Pen-Parents, Inc.

PO. Box 8738, Reno, Nevada 89507-8738

Tel.: (702) 826-7332

<http://pages.prodigy.com/NV/fgck08a/PenParents.html>

Centering Corporation

A small publishing business, the Centering Corporation provides families with printed resources (books, articles, and pamphlets) concerning grief and loss. Its materials are reasonably priced, easy to read, and available through mail order.

Centering Corporation

1531 N. Saddle Creek Road, Omaha, Nebraska 68104

Tel.: (402) 553-1200

APPENDIX 7

Glossary of Terms

Low birth weight. A fetus/baby is considered of low birth weight if he/she weighs less than 2500 grams at birth. The low birth weight rate is calculated as the number of live born infants weighing less than 2500 grams divided by the total number of live born infants. A fetus/baby is considered of very low birth weight if he/she weighs less than 1500 grams at birth.

Prematurity. A fetus/baby is considered premature/preterm if he/she is born before the 37th week of gestation. A fetus/baby is considered to be very preterm if he/she is born before the 32nd week of gestation.

Stillbirth. A fetus/baby is considered to be stillborn if he/she is born following at least 20 weeks of gestation or weighs at least 500 grams, and shows no sign of life at the time of birth.

Early neonatal death. A live born infant who dies before the seventh day following birth is classified as an “early neonatal death.”

Late neonatal death. A live born infant who dies on or after the seventh day following birth, but before the twenty-eighth day following birth is classified as a “late neonatal death.”