



CHAPTER 7
LOSS AND GRIEF



**TO PROMOTE AND PROTECT THE HEALTH OF CANADIANS THROUGH LEADERSHIP,
PARTNERSHIP, INNOVATION AND ACTION IN PUBLIC HEALTH.**

—Public Health Agency of Canada

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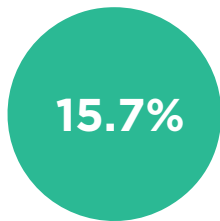
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CHAPTER 7

LOSS AND GRIEF

PERINATAL LOSS IN CANADA



15.7% of couples have problems with fertility



15-25% of pregnancies end in a miscarriage



Ectopic pregnancy occurs in approximately 1-2% of diagnosed pregnancies

IN 2014

Overall fetal mortality rate was **8.1 per 1,000** total births

Fetal mortality rate for *multiple births* (13.5 per 1,000 total births) was **much higher** than among *singleton births* (4.8 per 1,000 total births)

Congenital anomalies rate was for 430.5 per 10,000 live births

Preterm birth rate (<37 weeks) was **8.1 per 100** live births
 Very preterm birth rate (<32 weeks) was **1.2 per 100** live births

IN 2011

Infant mortality rate was **5.0 per 1,000** live births

Neonatal mortality rate was **3.6 per 1,000** live births

Post-neonatal mortality rate was **1.4 per 1,000** neonatal survivors

THE LEADING CAUSES OF

INFANT DEATHS:

Immaturity: **29.6%**
 Congenital anomalies: **21.7%**
 Other/unknown: **20.3%**

NEONATAL DEATHS:

Immaturity: **37.6%**
 Congenital anomalies: **21.4%**
 Other/unknown: **20.4%**

POST-NEONATAL DEATHS:

Congenital anomalies: **22.3%**
 Other/unknown: **19.7%**
 Sudden infant death syndrome (SIDS): **19.6%**

PRETERM BIRTH RATES AMONG:



Singleton was **6.3 per 100** live births



Twin was **56.7 per 100** live births



Triplet or higher order was **93.8 per 100** live births

For references consult **Chapter 7: Loss and Grief** in: Public Health Agency of Canada. Family-Centred Maternity and Newborn Care: National Guidelines. Ottawa (ON): PHAC; 2020.

For more information about the **Family-Centred Maternity and Newborn Care: National Guidelines**, or to download this document, please search “maternity and newborn care” on **CANADA.CA**.





FAMILY-CENTRED CARE FOR FAMILIES WHO EXPERIENCE PERINATAL LOSS

Supporting families through loss and grief is an integral part of Family-Centred Maternity and Newborn Care. Perinatal loss includes infertility during the preconception period, fetal death during pregnancy (miscarriage, ectopic pregnancy, induced abortion and stillbirth) and infant death in the first year of life (neonatal or post-neonatal death).

Principles for the care of families that experience a loss

1. Individualized care is provided to meet bereaved parents' personal, cultural and religious needs.
2. Compassionate communication with parents is important both before and after their loss.
3. Parents are given the information and support they need to make informed decisions about their own and their baby's care.
4. Accept and validate parents' feelings and make no assumptions about the intensity and duration of their grief.
5. Parents are cared for in an environment they feel is appropriate and private.
6. Ideally, the same health care providers (HCPs) are responsible for providing care during and following the loss.
7. The support meets the needs of partners or support people and families.
8. Parents have opportunities to create memories of their baby.
9. Parents are helped in performing rituals they consider important.
10. The remains of babies and fetuses are always treated with respect. Options around sensitive care and disposition of the baby after death are discussed.
11. Effective interdisciplinary communication is essential to ensure that all health care team members have accurate and current information.
12. Ongoing support is an essential part of care and is available to everyone, including during a subsequent pregnancy and after the birth of another baby.
13. HCPs involved in the care of bereaved parents have opportunities to develop and update their knowledge and skills, and have access to emotional support for themselves.

For references consult **Chapter 7: Loss and Grief** in: Public Health Agency of Canada. Family-Centred Maternity and Newborn Care: National Guidelines. Ottawa (ON): PHAC; 2020.

For more information about the **Family-Centred Maternity and Newborn Care: National Guidelines**, or to download this document, please search “maternity and newborn care” on **CANADA.CA**.

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Supporting families through loss and grief is an integral part of Family-Centred Maternity and Newborn Care. The emotional impact of perinatal loss is felt by parents, family members, friends and the health care providers (HCPs) caring for the bereaved family. For some parents and families, this is their first major bereavement and they are unfamiliar with the process and effects of grieving. The role of health care services and community organizations is critical in supporting families experiencing loss any time during the perinatal care trajectory.

Grief is the normal response to losing a loved one. The experience of loss is unique to each person and to the circumstances.¹ Grief reactions are not based on gestational age, age of the infant, socioeconomic or educational status, number of losses experienced or number of living children. Nor is there a right or wrong way to grieve after a loss.²

High quality bereavement care includes compassionate and open communication, with informed choice and individualized care.³ Compassionate communication, the most important element of bereavement care, is required in all aspects of care throughout and following the loss. It includes listening and providing clear information in a sensitive manner.

Effective communication between individual HCPs and care teams and services is also essential to ensure consistent care and accurate information about all available options. Parents and families need the necessary information and time to make the decisions that are right for them, their baby and their family.

Care and support should always be tailored to meet individual needs, preferences and, to the extent possible, cultural practices. It is important not to make assumptions about peoples' wishes and decisions. Institutional practices, protocols and practitioners' belief systems can be unhelpful and even harmful when what is required is empathy, compassion and providing the family with a sense of control.

> ADDITIONAL RESOURCES ON LOSS AND GRIEF: SEE APPENDIX A



1 PERINATAL LOSS

A significant portion of Canadian families experience a perinatal loss each year. Perinatal loss includes infertility during the preconception period, fetal death during pregnancy (miscarriage, ectopic pregnancy,

induced abortion and stillbirth) and infant death in the first year of life (neonatal or post-neonatal death). The type of loss does not predict or dictate a family's experience of the loss.

TYPES OF PERINATAL LOSS⁴⁻⁸

Prior to pregnancy

Infertility	The inability to conceive after 1 year of regular unprotected sexual intercourse.
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During pregnancy

Fetal mortality	An intrauterine death of a fetus at any gestational age.
Early pregnancy losses (<20 weeks of gestation)	Ectopic pregnancy: A pregnancy that occurs outside of the uterus; usually diagnosed in the first trimester.
	Miscarriage (spontaneous abortion): The death of a fetus in the womb during the first 20 weeks of pregnancy.
	Induced abortion: A procedure to terminate a pregnancy for personal reasons, a prenatal diagnosis of a fetus with a life-limiting anomaly or a significant maternal medical concern.
Late pregnancy losses (≥ 20 weeks of gestation)	Stillbirth: The death of a fetus at ≥20 weeks' gestation or ≥500 g birth weight that occurs prior to its complete expulsion of or extraction from the mother. ⁱ

After birth

Infant mortality	The death of an infant during the first year of life.
Infant deaths (0-364 days)	Neonatal death: The death of a baby who dies within 27 days of being born.
	Post-neonatal death: The death of a baby between 28 and 364 days of life.

i In Quebec, only deaths of fetuses weighing ≥500 g (i.e., stillbirths), regardless of the gestation period, must be reported.

In Canada, fetal mortality rate is defined as the number of fetal deaths per 1,000 total births (live births and stillbirths). All provinces and territories (excluding Quebec) require that all stillbirths with a birth weight of 500 g or greater or a gestational age at delivery of 20 weeks or greater be registered (including those following pregnancy termination). Quebec requires the registration of stillbirths with a birth weight of 500 g or greater and does not register pregnancy terminations.⁵

Infant mortality rate is defined as the number of deaths of live born babies in the first year after birth per 1,000 live births.

Comparison of the rates of pregnancy and infant loss is affected by the different definitions used provincially, nationally and internationally. Data from some Canadian provinces (e.g., Ontario, Quebec) are excluded because the provinces do not contribute to the Canadian Institute for Health Information–Discharge Abstract Database (CIHI-DAD) or because of data quality concerns. In addition, some rates are reported per total births (including stillbirths) or only per total live births.

1.1 LOSS PRIOR TO PREGNANCY

Infertility is the inability for a couple to conceive after 1 year of regular unprotected sexual intercourse for couples where the woman is aged less than 35 years and 6 months of regular unprotected sexual intercourse where the woman is aged over 35 years.⁴ In Canada, the overall number of people facing fertility problems or impaired fecundity increased by 10.3% between 1984 and 2009–2010. The percentage of couples with fertility problems was estimated at 5.4% in 1984, 8.5% in 1992 and 15.7% in 2009–2010, representing almost 1 in 6 couples.^{9,10}



Although the rate of infertility increases with women's age, the trend in rising infertility rates is not exclusive to older women. The infertility rate was 4.9% in 1984 among couples with a female partner aged 18–29 years and between about 7% and 13.7% in 2009–2010.^{9,10} Among couples with a female partner aged 40–44 years, the infertility rate was estimated to be between 14.3% and 20.7% in 2009–2010.¹⁰ In 1984, the rate was only 4.6%.⁹

Factors that adversely affect fertility include obesity, smoking, alcohol use and sexually transmitted infections.^{11–13} The most common causes of female infertility include problems with ovulation, damage to the fallopian tubes or uterus or issues with the cervix.¹⁴ The increase in the incidence of infertility is due, in part, to a delay in childbearing. Possible explanations for the postponement of pregnancy include couples starting to live together or getting married at older ages, readily available and effective birth control options and more women in the workforce.

1.2 LOSS DURING PREGNANCY

Fetal mortality is the intrauterine death of a fetus at any gestational age. Fetal death can be due to ectopic pregnancy, miscarriage, induced abortion or stillbirth. Between 2005 and 2014, the overall rate of fetal mortality fluctuated between 7.5 and 8.1 per 1,000 total births. The fetal mortality rate is significantly higher among multiple births (13.5 per 1,000 total births in 2014) than among singletons (4.8 per 1,000 total births).¹⁵ A fetal death may be a complete surprise, with no warning signs, that is diagnosed during a routine ultrasound scan; in other cases, women may notice decreased fetal movements or otherwise suspect that something is wrong.¹⁶

An ectopic pregnancy is a pregnancy that develops outside of the uterus, usually in the fallopian tubes. An ectopic pregnancy occurs in approximately 1–2% of diagnosed pregnancies.¹⁷ Parents may be frightened or distressed if they are waiting for the confirmation of a suspected ectopic pregnancy or receiving treatment for an ectopic pregnancy. Some parents may not have known they were pregnant. Sometimes, HCPs become so focused on the medical/surgical and potential life-threatening nature of ectopic pregnancy, they forget to address the fear and distress as well as the feeling of loss.

Spontaneous losses occur most frequently in the first trimester, with genetic defects the most common cause. Approximately 15% to 25% of pregnancies end in a miscarriage, and the rate increases with maternal age.¹⁸ The miscarriage rate may in fact be higher because many women do not know they were pregnant, but think they had a heavy menstrual period. In addition, some women choose not to disclose their miscarriage to their HCP.

Parents may feel many emotions during or following a miscarriage—grief, distress, shock, confusion, regret, anger, guilt, stress or mixed emotions.^{19–21} For some, these emotions may be intense or overwhelming.²¹ Others may feel relieved if the pregnancy was unwanted. Not all women or partners believe that a miscarriage represents the death of a baby. Regardless of what meaning they ascribe to the loss, all parents deserve the same degree of attention and support from HCPs.²²

An induced abortion is a procedure performed to terminate a pregnancy. The reasons may be personal (e.g., the pregnancy is unwanted, financial situation or relationship issues) or medical (e.g., a prenatal diagnosis of a life-limiting anomaly such as fatal syndromes, congenital anomalies; a significant maternal medical concern such that continuing the pregnancy would be hazardous to the mother's physical or mental health). The rate of termination of pregnancy with a birth weight of at least 500 g or 20 weeks gestational age has remained steady, ranging between 0.5 and 0.6 per 1,000 total births in 2005 and 2014, respectively.¹⁵



In all the provinces except Quebec, stillbirth is defined as fetal death at a birth weight of at least 500 g or a gestational age at delivery of at least 20 weeks and no signs of life (i.e., no heartbeat or breathing). In Quebec, stillbirth is defined as fetal death at a weight greater than 500 g irrespective of gestational age.⁵ National stillbirth rates have fluctuated at between 7.9 and 8.3 per 1,000 total births between 2013 and 2017.²³

Parents of multiples face a unique situation when 1 or more of their babies die. One of a set of multiples may die in utero or in the Neonatal Intensive Care Unit (NICU) after a premature birth.²⁴ In such situations, parents often feel torn between grief at the loss of the baby and joy at the survival of the other baby or babies. They may also feel afraid, guilty and helpless. When the death occurs in utero, some parents are unable to start grieving for the baby or babies who died until after the birth, possibly because they feel they cannot say goodbye or have a funeral.²⁵ Some parents worry that their fear or grief may affect the surviving baby or babies.²⁵ It is important for HCPs to acknowledge that parents' feelings are normal and to provide opportunities for parents to voice their concerns.

1.3 LOSS AFTER BIRTH

Infant mortality is defined as the death of an infant in the first year of life. Between 2002 and 2011, the infant mortality rate in Canada fluctuated between 4.9 and 5.4 per 1,000 live births. During that time, neonatal mortality rates fluctuated between 3.5 and 3.9 per 1,000 live births, while post-neonatal mortality rates fluctuated between 1.2 and 1.6 per 1,000 neonatal survivors. Neonatal mortality accounted for 73% of infant deaths in 2011.¹⁵

CONGENITAL ANOMALIES

Learning that a baby has a congenital anomaly (also known as a birth defect, a congenital disorder or a congenital malformation) can be devastating to families. Congenital anomalies are usually structural or functional.²⁶ They occur during intrauterine life and can be identified prenatally, at birth or later in infancy (e.g., hearing loss). Although approximately 50% of all congenital anomalies cannot be linked to a specific cause, some have known genetic, environmental or other causes or risk factors (e.g., maternal age, infections, maternal nutritional status).²⁶ Between 2005 and 2014, the prevalence of congenital anomalies in Canada fluctuated between 377.5 and 430.5 per 10,000 live births.¹⁵

Congenital anomalies are the second leading cause of infant mortality in Canada. Congenital anomalies detected prenatally may affect decisions about continuing the pregnancy. What parents decide to do when they learn about their baby's anomaly depends on factors such as the knowledge, attitude and communication style of the provider, the information they receive about the condition, their personal beliefs, culture and education level as well as available services and support.²⁷

After a baby is diagnosed with a congenital anomaly, parents often go through stages of grief similar to those they would have experienced if they had lost the baby. They mourn the loss of the "normal" healthy baby they were expecting.²⁷

Congenital anomalies can lead to long-term disability, significantly impacting individuals, families and health care systems.²⁶ Challenges families face include barriers due to bias, quality of life issues, finding resources and support, and helping their child transition to appropriate specialized adult care. It is important that information be provided to parents in clear, timely and sensitive ways that enhance collaborative decision making.²⁸

During 2007–2011, the leading causes of infant deaths overall were immaturity (29.6%), congenital anomalies (21.7%) and other/unknown factors (20.3%). The leading causes of neonatal deaths were immaturity (37.6%), congenital anomalies (21.4%), and other/unknown (20.5%), while the leading causes of post-neonatal deaths were congenital anomalies (22.3%), other/unknown (19.7%) and sudden infant death syndrome (SIDS) (19.6%).¹⁵

Preterm birth (before 37 completed weeks of gestation) continues to be a significant cause of infant death in Canada. Between 2005 and 2014, the rate of preterm birth fluctuated between 8.0 and 8.3 per 100 live births.¹⁵ Most preterm births were delivered between 32 and 36 weeks gestation, with the rate ranging from 6.8 to 7.0 per 100 live births. During the same period, the rate of very preterm birth (<32 weeks) remained stable at 1.2 per 100 live births.

Preterm birth rates are considerably higher among multiple births. Preterm rates among singleton, twin and triplet or higher order live births were 6.3, 56.7 and 93.8 per 100 live births, respectively, in 2014. Between 2000 and 2013, preterm births accounted for the highest proportion of births among mothers aged 35–49 years, followed by mothers less than 20 years old and then mothers aged 20–34 years.²⁹



All preterm infants are at greater risk than term infants for lifelong health problems. Medical problems associated with preterm birth include respiratory distress syndrome, chronic lung disease, cardiovascular disorder, asthma, and hearing and vision loss.^{30,31} Early births also take a financial toll on families. Emotional tolls can be exacerbated by the lost weeks of pregnancy that would have been spent preparing for parenthood, the inability to take the baby home immediately after birth due to the need for specialized care, financial burdens and the potential or real possibility of the infant dying.¹

In NICUs, infant death commonly occurs after a decision is reached to limit or withdraw life-sustaining treatments when it becomes evident that continuing treatment may prolong the baby's suffering without improving his or her quality of life.³² These types of decisions can be ethically challenging and morally distressing for parents and HCPs.³³ Helping parents with these decisions through an interdisciplinary, family-centred approach can reduce the provision of ineffective and unnecessary interventions and reduce the suffering of both babies and parents.^{33,34}

HCPs can also help prepare parents by initiating discussions of how their baby will be cared for, including pain management, when limits to or withdrawal of life-sustaining treatments are being considered. It is important to advise parents that it is difficult to predict how soon a baby will die following withdrawal of life support.³⁵ When duration of survival is uncertain, it is necessary to prepare them for the possibility that their baby may survive for longer than they may expect.

A perinatal psychologist or clinical ethicist can play a significant role in assisting the family and the attending HCPs.³⁶



2 PRINCIPLES OF CARE FOR FAMILIES EXPERIENCING A LOSS

The support and care that parents receive around the time of a perinatal loss is crucial as it may affect their long-term wellbeing.^{15,37} In order to provide holistic care that is sensitive to individual needs, it is important to take a family-centred integrated approach.

A family-centred approach requires that HCPs consider parents' personal, cultural, spiritual and religious needs and be aware of how these may affect their decisions on care for themselves and the baby who has died or is expected to die. Parents' opinions and beliefs may affect the decisions they make regarding antenatal

screening and diagnostic testing, miscarriage, termination of pregnancy, continuing a pregnancy after a fetal anomaly is diagnosed, postmortem examinations or funeral practices.³ These factors may also influence how parents express emotions and grief or how they view themselves as parents.

The role of integrated care—ensuring good coordination, cooperation and communication between and within services provided by health care services, social care systems and local and national support organizations—is also crucial when providing holistic care.³⁸



PRINCIPLES FOR THE CARE OF FAMILIES THAT EXPERIENCE A LOSS^{3, P.11,15,18,39,40}

1. Individualized care is provided to meet bereaved parents' personal, cultural and religious needs.
2. Compassionate communication with parents is important both before and after their loss. This means information is communicated sensitively and clearly and is tailored to meet the individual needs of parents, using the language they use when discussing their baby or fetus. HCPs are careful to avoid using terms that may be misinterpreted or considered inappropriate.
3. Parents are given the information and support they need to make informed decisions about their own and their baby's care. The HCP ensures parents' concerns are heard and addressed.
4. HCPs accept and validate parents' feelings and make no assumptions about the intensity and duration of their grief. Responses are personal and not determined by the gestational age or infant's age.
5. Parents are cared for in an environment they feel is appropriate, ideally in a single room or dedicated bereavement room for the sake of privacy.
6. If possible, the same HCPs are responsible for providing care during and following the loss. Parents can benefit from the support of a continuous team of HCPs who are trained in providing bereavement care and are comfortable offering anticipatory guidance.
7. The support meets the needs of partners or support people and families.
8. Parents have opportunities to create memories of their baby.
9. Parents are helped in performing rituals they consider important.
10. The remains of babies and fetuses are always treated with respect. Options around sensitive care and disposition of the baby after death are discussed.
11. Effective interdisciplinary communication is essential to ensure that all health care team members have accurate and current information. This means that all involved in caring for the family know their preferences and decisions, and parents do not need to repeatedly explain their situation. A seamless and informed handover of care from the hospital to the community is equally important.
12. Ongoing support is an essential part of care and is available to everyone. Support is available to all women and their partners during a subsequent pregnancy and after the birth of another baby.
13. HCPs involved in the care of bereaved parents have opportunities to develop and update their knowledge and skills and have access to emotional support for themselves.



3 GRIEF AND MOURNING

A loss during pregnancy or infancy is a complex and unique tragedy that profoundly affects parents as individuals, as couples and as families.^{41,42} The death of an unborn baby or newborn can represent the loss of a significant person and a family member and the loss of hopes, dreams and expectations for the future. The loss may extend to some aspect of self, the loss of self-esteem, the loss of a stage of life or a failure in parenting.⁴³⁻⁴⁶ This may be the first time parents have felt bereaved and the first time they experience emotional turmoil and devastation

3.1 THEORIES OF GRIEF

Several theories and frameworks help HCPs understand why perinatal loss is unique and how it can affect bereaved families, as well as the HCPs who care for them. The focus of models of loss and bereavement has gone from theories of attachment and loss, to concepts of acute grief, to tasks of mourning, to stages, to psychological processes and phases.

THEORIES OF GRIEF ⁴⁷⁻⁵⁶

Theory	Description
Attachment Theory	<ul style="list-style-type: none"> Emphasizes the interrelationships between attachment, affectional bonds, separation and loss in human relationships. Provides a framework for understanding the grief and bereavement that people feel and how these relate to pre-existing relational bond.
Psychodynamic Theory	<ul style="list-style-type: none"> Provides an introspective view of the process of coping with any loss in an adaptive manner. Conceptualizes that the duration and intensity of the grieving process force a psychological restructuring of self.
Interpersonal Theory	<ul style="list-style-type: none"> Offers a lens through which to understand the impact prolonged depression (or events that contribute to similar symptoms) can have on interpersonal relationships as well as social relations. Focuses on addressing the experience of symptoms as well as social adjustment and interpersonal relations.
Cognitive Stress Theory	<ul style="list-style-type: none"> Stipulates that any stress-inducing situation requires cognitive processing and restructuring. “Cognitive schemas” that guide thoughts, beliefs and assumptions about the origin and outlook of events are used to help make sense of the world.

THEORIES OF GRIEF⁴⁷⁻⁵⁶

Theory	Description
Five Stages of Grief ⁵²	<ul style="list-style-type: none">• The stages of grief typically experienced are denial, anger, bargaining, depression and acceptance.• Individuals do not necessarily go through all these stages in an orderly manner; the experience of grief is varied and unpredictable.
Dual Process Model of Coping	<ul style="list-style-type: none">• Bereaved people alternate between 2 coping modes: loss orientation (focused on adjusting to a loss) and restoration orientation (focused on how to move on in light of the loss).• Oscillation is a dynamic process where grief work and confrontation overlap. Both are necessary in adaptive grief work, that is, adjusting to life without the loved one.
Tasks of Mourning	Individuals accomplish 4 tasks in order to complete the process of mourning and for equilibrium to be restored: <ul style="list-style-type: none">• Accepting the reality of the loss;• Processing the pain of grief;• Adjusting to the world without the deceased; and• Finding an enduring connection with the deceased while moving forward with life.
Theory of Caring	<ul style="list-style-type: none">• Caring: “nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility.”^{55,p. 165}• Involves 5 caring processes: knowing, being with, doing for, enabling and maintaining belief.

3.2 EXPRESSIONS OF GRIEF

Grief is a multifaceted response to loss that affects the entire person. It includes physical, emotional, intellectual, spiritual, social and occupational elements.⁵⁷ While grief can affect a person’s emotional and mental wellbeing, it is a normal response to bereavement.

The experience, expression and intensity of grief following a perinatal loss are unique to each individual.^{3,58} Grieving style is formed by a person’s culture, personality and gender. Individuals need to be allowed to express grief in their own way.

Some parents and family members have mental health problems following a loss during pregnancy or in infancy. Some of the more common mental health problems that affect bereaved parents include prolonged grief, clinical depression, anxiety disorders and post-traumatic stress disorder. It is incumbent upon HCPs to assess bereaved parents and offer treatment.³ Ideally, parents are referred to mental health professionals (e.g., counsellors, psychologists, mental health support workers, psychiatrists) with perinatal bereavement training who understand the unique experiences and challenges the family may be facing.³

3.3 GRIEF EXPERIENCES OF PARENTS

Parental grief has been recognized as the most intense and overwhelming type of grief.⁵⁹ Because individuals grieve in different ways, parents' reactions may be incongruent even though both have had the same loss.⁶⁰ The depth and length of each parent's grief depends to some extent on their personality, life experiences and previous experiences of loss, attachment to the baby or to pregnancy, the significance and circumstances of the loss and the support network available to them.⁵⁴

It is often assumed that partners bond less deeply than mothers with an unborn child and that they are less severely affected by a loss, especially one that occurs early in pregnancy.⁶¹ In fact, many partners grieve deeply and intensely in response to the death of their baby.⁶² Partners may believe they must put their grief on hold in order to support the mother and focus on other practical tasks.^{58,63-65} Gender expectations may also affect men's ability to acknowledge their own needs. Men may feel they have to be the supporter or strong when faced with a pregnancy loss. Continued research is needed on how men experience pregnancy and infant loss, including the experiences of gay and transgendered men.⁶⁶

As a protective mechanism from the pain of loss and grief, parents may withdraw emotionally and physically from the experience or from the family.⁶³ A perinatal loss may create an added strain on the couple's relationship or it may strengthen it.^{63,67-70} Some parents have difficulties in their relationship if both do not have the same experiences of grief and are unable to accept each other's different ways of grieving or do not feel they have support from their partner. The parents may also experience sexual difficulties after a loss that affects their relationship.⁷¹

Although the intensity of grief can ease with time, it can also fluctuate depending on circumstances.^{58,64} Significant dates such as the baby's due date, the date the baby died, the baby's birth date, Mothers' day, Fathers' day, family celebrations and important life events may trigger parents' feelings of grief.

3.4 GRIEF EXPERIENCES OF OTHER FAMILY MEMBERS AND OF FRIENDS

Siblings

Children are usually profoundly affected when their parents are grieving. Just like adults, children's grief response can range from a minor reaction to feeling their world has shattered. Siblings in bereaved families suffer 2 losses: the sibling they were expecting and their parents as they knew them before their sibling's death.⁷² Children's response to loss is determined by their personality, age, developmental stage and how the family is coping. Children often cope with grief and loss through play. Support from adults is important as they learn how to grieve from the adults that surround them. While many people want to protect children from the reality of death, as with adults, it is important to provide children with clear, developmentally appropriate explanations for the loss and involve them in memory making and legacy building. How much children are involved in rituals after a loss depends to some extent on age, personal preferences and cultural norms.

“ Children's response to loss is determined by their personality, age, developmental stage and how the family is coping.

Grandparents

Many grandparents are deeply affected by a perinatal loss. For some, the loss evokes painful memories of their own losses for which they did not receive adequate support. Grandparents often grieve for their much anticipated grandchild and for their child whose baby has died.^{44,58} They may feel distress in their inability to lessen their child's pain and grief. Grandparents may want to see and hold the baby and participate in the funeral, memorials and other rituals.

Extended family members and friends

For some families or cultures, there is no division between immediate and extended family, and grandparents, aunts, uncles, siblings and cousins are all regarded as close family, with a new baby considered an addition to the whole family.

For some people, the definition of family may also include close friends. This means that a larger number of people than anticipated may be grieving over the death and want to be directly involved.

3.5 ASSESSMENT OF THE BEREAVED FAMILIES' CARE AND SUPPORT NEEDS

A detailed assessment of the family's grief reactions helps HCPs understand the meaning that each family member has ascribed to the perinatal loss. Such an assessment includes physical, emotional, intellectual, spiritual and social components. A continuous assessment ensures that the care and support provided in the hospital and the community is appropriate and meets family members' needs.



ELEMENTS OF GRIEF AND LOSS NEEDS ASSESSMENT

Social assessment:

- The person's past experiences and customary way of dealing with death or other crisis situations
- The cultural or religious practices that the person may wish to observe or that may constrain them
- The person's past perinatal and other losses, which may influence the grieving process
- The relationships between partners, children and grandparents (and the involvement the parents wish others to have in the grieving process)
- The family support system
- The ages of other children and how the parents plan to explain the death to them

Psychological assessment:

- Where the parents and the family are in their grieving process
- Help families and supporters accept their feelings, understand the importance of expressing these feelings, and gain hope that the pain will diminish

Physical assessment:

- The physical effects of pregnancy, labour and birth and the state of the mother's health during the early postpartum period. This might include excessive bleeding or cramping following a D & C, exhaustion following a long and difficult labour, pain following a caesarean birth and breastmilk production
- The medications taken that might dull her perception of events and limit her ability to recall the details of her loss
- Recognition of any health problems that might affect the mother's ability to conceive and bear children in the future

Spiritual assessment:

- May be easily overlooked, especially if the person does not profess affiliation with a recognized group
- A person's spiritual nature is broader than organized religions; all individuals have a spiritual self with needs that are likely to be heightened at the time of perinatal loss
- Determine:
 - > What gives meaning to life for the woman and partner
 - > The kind of faith held by the woman and partner, and the strength of this faith
 - > If their faith is part of an official religious affiliation. If so, what rites are necessary to fulfill the beliefs of this religion
 - > What meaning the parents place on this loss
 - > To what factors they attribute the death



4 COMMUNICATION

It is essential that HCPs who care for and support bereaved parents apply compassionate communication strategies: consider what is said (verbal communication), how it is said (non-verbal communication including elements such as tone of voice and body language) and the context (the physical environment, cultural factors and developmental factors).^{15,37,73} In order to create a climate of trust, the behaviours, language and timing as well as how much and the way information is provided are important factors affecting parents' experiences of care. Allowing enough time to process the information also promotes feelings of being cared for.¹⁵

Parents appreciate when HCPs talk with them in a sensitive but clear and honest manner.³¹ It is important that HCPs consider the possible impact of the words, terms and phrases they use.^{36,37} A sentence that seems inoffensive and practical when speaking to a colleague may be disturbing for bereaved parents. For example, although the terms the *products of conception*, *the embryo* or *the fetus* are clinically correct, they may be distressing for the family. If the baby has been named, parents may consider it important that they and HCPs use his or her name, spell the name correctly and refer to the baby by the appropriate gender pronoun.³¹ Other parents

may feel more comfortable using the clinical expressions (e.g., “the fetus”), while other parents may prefer to think of their loss as the end of a pregnancy rather than the death of a baby.

Posture, gestures, facial expression and tone of voice are the non-verbal communication cues that can affect how bereaved parents perceive and understand the information HCPs are conveying.^{37,74} Parents may discount information if body language does not conform to what is being said. HCPs need to be conscious of the cues and behaviours they display, as individuals may interpret components of non-verbal communication in different ways (i.e., cultural differences in the meanings of touch, some gestures, facial expressions and eye contact).



COMMUNICATING WITH FAMILIES EXPERIENCING A PERINATAL LOSS⁷⁵⁻⁷⁷

What to Say	What Not to Say
<ul style="list-style-type: none"> • “I’m sorry” or “I’m sorry for your loss” • “I wish things had turned out differently” • “I feel sad” or “I am sad for you” • “How are you doing with all of this?” • “Can you tell me about what you are feeling?” • “Can you tell me what happened today?” • “What is going on right now?” • “What is the hardest part for you right now?” • “What can I do for you?” or “How can I help?” • “I’m here and ready to listen” • “Do you have any questions?” • “Can I call someone for you?” • “What do you need right now?” • “We can talk again later” • “Take all the time you need” • “We are here to help” • “Call us if you need us” • “Tell me about your supports at home” • “It’s ok to cry” 	<ul style="list-style-type: none"> • “This happened for the best” or “Everything happens for a reason” • “This is nature’s way” • “This is God’s will” or “God knows best” or “God needed an angel” • “It could be worse” • “At least it all came out” • “At least you didn’t know the baby” • “You’re young, you can try again” or “You can have more children” • “Time will heal” • “You have an angel in heaven” • “It’s good your baby died before you got to know him / her well” • “It was not meant to be” • “Over time you will forget your baby” • “It’s just your body’s way of ending an unhealthy pregnancy” • “This happens all the time” • “Be grateful for the children you have” • “You need to move on”
What to Do	What Not to Do
<ul style="list-style-type: none"> • Acknowledge the person’s loss • Listen more than talk • Answer questions honestly or refer to someone who can • Allow time for discussion and support • Offer practical assistance (food, calling someone) • Be comfortable showing genuine care and emotion • Be comfortable touching the baby • Think about a follow-up plan • Use simple and straightforward language • Repeat information as needed • Contact the family when you say you will • Call the baby by the name/term the parents prefer 	<ul style="list-style-type: none"> • Dominate the conversation • Use clichés • Pass judgment • Minimize the loss • Change the subject • Avoid the family • Take anger personally • Give medical advice without knowledge • Avoid questions • Argue with parents and their families • Ignore or forget other family members (partners, siblings, grandparents) • Use medical jargon

4.1 LISTENING

Listening is a crucial part of communication. It is essential support for bereaved parents. Parents require opportunities to discuss their concerns, needs, feelings, experiences and wishes regarding care for themselves and their baby.

HCPs actively listen and offer support to bereaved parents by being attentive; using appropriate eye contact; adopting attentive body language (e.g., leaning forward slightly, nodding); not interrupting while the parents are speaking; giving verbal cues (e.g., “I see”); avoiding introducing new topics of conversation until the parents are ready; taking parents’ concerns seriously; and adopting communication methods that encourage or clarify the conversation (e.g., open questions, paraphrasing, use of minimal encouragers, reflection of feeling, therapeutic silence).^{3,78}

4.2 BREAKING BAD NEWS

Bad news may be defined as “any information which adversely and seriously affects an individual’s view of his or her future”.⁷⁹

Breaking bad news is a complex communication task. HCPs will want to ensure that they have the privacy and time to convey bad news; respond to parents’ emotional reactions; include them in decision making; help them deal with the stress created by their expectations; and allow for the involvement of multiple family members. Also important is the dilemma of how to provide hope when the situation appears bleak.⁸⁰

Although breaking bad news is frequently necessary, this responsibility poses a major challenge and can create difficult, painful situations. One of the hardest aspects of breaking bad news is not knowing how parents will react (i.e., will they be silent, tearful, angry, disbelieving or distressed and will they feel guilty or blame themselves or other people).

Communication is a process that requires time and effort. It is best to offer information about the baby’s condition in small increments, rather than a “single or isolated act” given all at once, taking care to avoid medical jargon but using terms the parents can understand. Allow time for parents to process the information and grieve, and give them opportunities to express their feelings, share their concerns and determine a strategy for the care of their baby.⁸¹⁻⁸³

It is important that HCPs be trained and prepared to face these difficult situations with the skills to sensitively inform parents when something is wrong. Regardless of the circumstances and the parents’ reactions to the news, remaining calm and supportive is key. The “Setting, Perception, Invitation, Knowledge, Empathy, Summary and Strategies” approach attempts to lessen the confusion parents feel and provide authentic empathy to alleviate some of the family’s grief.

“ Allow time for parents to process the information and grieve, and give them opportunities to express their feelings, share their concerns and determine a strategy for the care of their baby.

SPIKES^{75-77,81-83}

Setting	Consider the optimal setting to deliver bad news including timing, privacy of location, presence of pertinent family members and freedom from distractions.
Perception	Use open-ended questions to elicit the woman's or family's perception of the situation and medical diagnosis.
Invitation	Ask the woman or family how much and what kind of information they want to know.
Knowledge	Provide medical knowledge in a manner that is sensitive to educational level, culture, ethnicity, religion and values. Ascertain understanding.
Empathy	Respond with empathy and use active listening, providing the necessary time, space and resources for emotional responses.
Summary and Strategies	Summarize decisions, allow time for questions, schedule follow-up meetings, provide information on resources such as support groups, and provide a concrete plan for the future.

4.3 PROVIDING INFORMATION AND FACILITATING INFORMED CHOICE

HCPs will want to communicate information about test results, diagnoses and available procedures or care options with consistency, sensitivity, honesty and clarity.³ Recognize that different sets of parents will have varying information requirements—all communication should be tailored to meet these specific needs and wishes.³

Verbal explanations are key to high quality bereavement care. Information in hardcopy (e.g., pamphlets, brochures) and other formats (e.g., websites, mobile applications, DVDs) may be useful resources for some people, especially those with sensory or learning disabilities. Despite the potential benefits of such resources, they should be considered a complement to, and not a substitute for, regular face-to-face discussions.³

HCPs can help parents make informed choices by:³

- Ensuring that parents are provided timely, accurate and unbiased information about the situation including all available care options or procedures and the potential benefits and risks related to these;
- Being sensitive when providing information;
- Using clear, explicit language;
- Verifying with each parent if additional support is required to help in their decision making;
- Being careful not to overload parents with information;
- Repeating information to parents as necessary; and
- Providing access to specialists as required.

4.4 COMMUNICATION BETWEEN MEMBERS OF THE INTERDISCIPLINARY TEAM

Providing high quality bereavement care requires that all members of the interdisciplinary team involved in caring for the family be well informed, work collaboratively and communicate effectively with each other. Poor communication may add to bereaved parents' distress and cause them to be traumatized through exposure to unnecessary enquiries or insensitive comments.³

All members of the interdisciplinary team have a responsibility to share relevant information with other team members and document, in medical records, discussions with parents and decisions taken. Regular reviews of the mother's or baby's medical records ensure that they are up to date and include what parents have been told and what decisions have been made.

When there is a transfer of care from one team, unit or service to another, it is essential to also immediately transfer all medical records, including any specific decisions or requests the parents have made and details of any investigations, test results and treatments. The woman's primary care provider (e.g., family physician or nurse practitioner who can provide ongoing follow-up care and support in the community) also needs to be notified.

Ideally, all units and healthcare services have in place policies and procedures to ensure the prompt and efficient transfer of information. When a referral is made or parents are being discharged from the health care facility, immediately inform (with the mother's informed consent) all relevant HCPs by telephone, followed as soon as possible by a written discharge letter. The letter would include a full history of the woman's or baby's care and postmortem examination/test results (if applicable), and information about the condition, follow-up plan, health care services offered, and recommended support services including contact coordinates.³



5 HELPING FAMILIES PLAN FOR LOSS

In instances where a perinatal death is anticipated (i.e., prenatal diagnosis of a fetus with a life-limiting anomaly or a genetic disorder, extremely preterm infants), HCPs can help families prepare for the impending loss by providing sensitive, respectful and well-coordinated care and support.^{84,85}

Waiting for follow-up tests (e.g., repeat ultrasound) to confirm a possible diagnosis of a fetal anomaly is emotionally difficult. The best outcomes will be achieved when the care provided is individualized to address the parents' needs and their specific situation with, wherever possible, their particular requests accommodated.³

WHEN HELPING FAMILIES PLAN FOR A PERINATAL LOSS, CONSIDER:¹

- The family's cultural and spiritual beliefs
 - The family's level of acceptance of their baby's condition
 - The support the members of the family get from one another and from others
 - The family's acceptance that the goal is their baby's comfort and care, rather than a cure
-

5.1 BIRTH PLANS

An individualized birth plan sets down parents' wishes and desires for the upcoming birth. A death that occurs during pregnancy necessitates establishing a birth plan with a different outcome. The family's participation in creating a plan may give them some sense of control. Following the plan allows HCPs to honour the family's choices for their baby without repeatedly asking them for direction. [Appendix B](#) provides a sample birth plan for pregnancy loss.

5.2 PERINATAL AND NEONATAL PALLIATIVE CARE

Perinatal palliative care, often referred to as perinatal hospice care, requires the provision of family-centred care for those who choose to continue a pregnancy after their baby is diagnosed with a life-limiting condition. It includes anticipating, preventing and relieving suffering (physical, psychological and spiritual), preserving dignity and promoting quality of life for the baby and family, while respecting the parents' choices and wishes.⁸⁶

Perinatal palliative care emphasizes creating a relationship with parents and guiding them in making decisions. Depending on the setting and community, the perinatal palliative care team may include nurses; midwives; physicians (maternal-fetal medicine, OB/GYN, neonatology, pediatrics, family medicine); genetic counsellors; social workers; chaplains; spiritual leaders; child life specialists; doulas; psychologists and other psychotherapists; funeral directors; and volunteers.⁸⁶ Bereavement support begins at the time of suspected or actual diagnosis and continues through follow-up care after the baby dies.⁸⁶

As with perinatal palliative care, neonatal palliative care can be offered when a baby is quite ill and likely to die. The goals of palliative care are quality of life, comfort or relief from symptoms, and support with tasks and bereavement.⁸⁷ Although the development of a palliative or end-of-life care pathway or plan may help parents and HCPs, these are not meant to be used as 'checklists' where all the items or interventions must be completed.⁸⁸⁻⁹⁰ Instead, such guides serve as prompts for ensuring babies and their families receive the best care.

Some NICUs include perinatal psychologists as full-time members of their staff to help both parents and HCPs cope with the care of babies who are ill and dying.³⁶

Collaboration across disciplines and agreement on the plan of care is critical to providing quality neonatal palliative and end-of-life care. It is essential that NICUs have in place policies to ensure good communication between members of the health care team involved in decision making about a baby's care.⁹⁰ Including parents in decision making shifts the focus from HCPs to the family and can help defuse professional disagreements.



If possible, parents should have the option of taking their baby home or to a hospice.^{91,92} NICUs need policies to ensure that HCPs know of, and can refer parents to a hospice that support parents before and after their baby's death. Pediatric hospices (e.g., Canuck Place, Roger Nielson House, La maison André-Gratton) and Ronald McDonald houses across Canada have care programs that assist families with children who are terminally ill or dying.

The organization Together for Short Lives has developed *Perinatal Pathway for Babies with Palliative Care Needs*; this is guided by the *Standards Framework for Children's Palliative Care* that includes specific standards for babies with palliative care needs.⁹³



6 CARE AT THE TIME OF THE LOSS

At the time of loss, parents need compassionate support and care from HCPs who listen and understand and provide guidance when asked. Parents should be attended in a dedicated and private bereavement care room that is adequately soundproofed so that they cannot hear babies or other parents.¹⁵ It is also important to consider the practical needs of partners or birth partners who may be spending many hours with the bereaved parents (e.g., comfortable chairs, toilet facilities nearby, access to meals).³

The quality of the care that parents receive immediately after a miscarriage, termination, stillbirth or neonatal death is crucial. This support may have long-term effects on parents' emotional and mental health.^{15,37}

It is critical that parents have the necessary time to make informed decisions at their own pace.³ HCPs can support parents by suggesting options and guidance in the hours after the death.⁹⁴

That said, parents benefit from the continuous support of a limited number of effective HCPs to minimize the number of interactions.⁸⁴

6.1 PROVISION OF EMOTIONAL SUPPORT

HCPs can offer emotional support in many ways to parents who have lost a baby:³

- Listen and be prepared to listen again and again;
- Accept what parents and family say without judgment, but correct factual misconceptions and misunderstandings;
- Acknowledge the parents' feelings and respond with empathy, expressing sympathy and sorrow;
- Avoid assumptions, clichés and empty reassurances;

- Remain calm when parents express strong feelings;
- Be genuine and willing to help and show compassion and kindness;
- Support parents in making informed choices; and
- Resist the temptation to give advice unless specifically asked.

The support offered should be based on the needs of parents so that they can maintain a measure of control over their own care.

When offering and providing emotional support to parents, it is important that HCPS remember that grief can be expressed in different ways and to avoid assumptions based on parents' outward expressions of grief. Some parents may be open about their feelings, while others may not show any outward signs of emotion while hurting deeply inside.

6.2 SEEING AND HOLDING THE BABY

Ask bereaved parents whether they wish to see or hold their baby. Offering this opportunity needs to occur within the context of relationship-based care, supportive conversations with parents, respect for their autonomy and support for them throughout the process.^{3,77,95,96} Cultural and religious variances should be taken into account to the full extent possible. In some cultures, close contact with a dead body is prohibited, while in others, it is considered the highest form of respect to remain with a body until burial.

If parents decide to see and hold their baby, contact should not be restricted. Parents deserve to hold their baby for as long or as short a time as they wish.⁷⁷ A growing number of hospitals are now providing parents with specialized cooling cots to allow them to spend more time making memories with their baby.⁹⁷

The Pregnancy Loss and Infant Death Alliance has released a position statement on supporting parents in spending time with their baby.⁹⁸

6.3 CREATING MEMORIES

Many bereaved parents want to cherish their baby and preserve his or her memory and importance in their lives.⁹⁹⁻¹⁰² Parents appreciate having photos and often express regret if these were not provided by the hospital.⁹⁹ Many find creating and sharing mementoes of their deceased baby helpful in their grieving process.^{103,104} Mementoes can include bathing and dressing the baby; talking to the baby and using the baby's name; engaging in religious or naming ceremonies; introducing the baby to extended family; and capturing interactions in photographs and videos.⁶⁹

Parents often decide to choose a meaningful name for their baby. The name may be gender-neutral if the sex of the baby is unknown. HCPS should always use the baby's name when parents have told them what it is.³

PERINATAL LOSS MEMENTOES

- Photographs, videos or ultrasound images
- Clothing (e.g., gown, sleeper, hat, booties, mittens, diaper, blanket) or a piece of embroidery or patchwork
- Ink footprints or handprints or foot or hand moulds—2D or 3D
- Measuring tape with inscribed length or crib card, with height and weight documented
- Copy of fetal monitor tracing
- Lock of hair or bottle of baby shampoo/soap
- Baby ring, angel pin, ceramic heart or naming bracelet/name blocks
- Stuffed animal
- Sympathy cards or inspirational sayings or poems/letters
- Certificates (Blessing/baptism rituals, certificate of life)
- Memory journal or memory box about the pregnancy, birth or the baby's life and death
- Forget-me-not seeds to plant
- Candle
- Copies of music played at the bedside

Protocols, procedures and bereavement checklists have been created to ensure that parents have choices. [Appendix C](#) provides a sample checklist. This and other checklists can be used to make suggestions to parents.¹⁰⁵ They are not meant to be adhered to as directives, rules or tasks that must be completed—at the end of the day, parental choice is paramount.³ For example, while many parents will choose to retain mementoes of their baby, others may decline on personal, cultural or religious grounds.¹⁰⁶

6.4 FAMILY INVOLVEMENT

After losing a pregnancy or baby, some parents want to be alone while others find comfort and support in having extended family and friends around them. HCPs will want to determine the parents' needs and then support them in doing what they feel is right for them. HCPs can help family and friends understand the types of support the bereaved parents usually require (e.g., suggest avoiding statements that minimize the parents' experience, explain the benefits of small gestures of kindness).¹⁰⁷

6.5 RITUAL AND SERVICES

Most bereaved parents who participate in rituals find support, meaning and facilitation of their grief.^{59,64,108,109} Participating in such rituals acknowledges the reality of the baby's death, provides social support, encourages the expression of emotions and helps convert the relationship with the baby from presence to memory.¹¹⁰

HCPs need to be aware of services available at their institution and discuss all available options with parents. By helping parents arrange services and participate in their chosen rituals, HCPs have the unique opportunity to support grieving parents.¹¹¹

INDIGENOUS CULTURAL CONSIDERATIONS

Many Indigenous teachings explain that the creation of life is sacred. For First Nations people, it represents the beginning of a new journey. A baby is a gift of the Spirit to parents and the community. When a baby dies, it is a tragedy for the whole community.

Some Indigenous peoples believe that when an individual dies, that person's spirit stays around for 4 days. During this time, the funeral and related traditional ceremonies need to take place to help remember and honour the person and the person's spirit.

Each First Nations, Inuit and Métis community has its own cultural and religious beliefs, rituals and ceremonies. Traditional rituals include smudging, sweat lodges, feasts, condolence ceremonies, "wiping the tears" ceremonies, journey ceremonies, songs and prayer. Medicines, sage, sweet grass, cedar, herbs and grief tea are also used to help with the grief.^{112,113}

It is important that HCPs familiarize themselves with the customs and traditions of Indigenous families they care for and provide culturally sensitive care.

Funerals and memorials are the customary rituals to ease the transition when a death occurs.¹ These events can occur shortly after the death or they may be postponed. It is important to consult and involve the hospital chaplain or local religious advisers for guidance and to help provide culturally sensitive care for different faith traditions.

Some parents may wish to organize a funeral or ceremony for their baby, regardless of the length of gestation or nature of their loss. Other parents will decide not to have a service for their baby.

Bereaved parents may choose to commemorate and remember their baby in some of the following ways:³

- Framing or hanging a photograph, drawing or painting of the baby
- Making a memory book or memory box about the pregnancy or birth or the baby's life and death
- Pressing flowers from the baby's funeral to keep or to display in a frame
- Making an embroidery or piece of patchwork
- Writing or framing a poem or letter to the baby
- Making, buying or commissioning a picture, sculpture, engraving or piece of jewellery
- Lighting a candle on anniversaries or other special days
- Putting flowers on the baby's grave, in the crematorium grounds or in a special vase on anniversaries and other significant dates
- Visiting a special place or sending flowers or a gift to a hospital or hospice on anniversaries
- Planting a tree or shrub
- Putting up a bench with a memorial plaque in a well-loved place, in the cemetery where the baby is buried or in the crematorium grounds
- Raising money or donating to a charity in memory of the baby
- Keeping the baby's ashes

Some hospitals and not-for-profit organizations hold an annual act of remembrance (e.g., awareness walk/run; butterfly release; family picnic; candle-lighting ceremony) or memorial service to which all bereaved parents are invited. It is important that these events remain open and suited to the needs of bereaved parents from different backgrounds who have experienced any type of loss.

6.6 ORGAN AND TISSUE DONATION

Deceased term or near-term babies can be considered for organ and tissue donation, and donation can be discussed with parents if their baby meets the relevant criteria. Parents often consider organ and tissue donation to be a positive event following their baby's death.¹¹⁴⁻¹¹⁶

That being said, the subject of organ and tissue donation must be broached with the utmost sensitivity, compassion and respect. When discussing this option, HCPs will want to carefully adhere to ethical principles to avoid conflicts of interest and ensure that families are free to make a fully informed decision that is consistent with their values and beliefs.

It is important that HCPs familiarize themselves with the details of the donation after circulatory determination of death (DCDD) in order to be able to effectively keep parents informed.¹¹⁴⁻¹¹⁶ Discussions in the period leading up to the planned organ recovery procedure should focus on end-of-life care and how DCDD will affect the process (e.g., whether the parents can hold the baby before determination of death, the inclusion of music, personal mementoes, parents' desire to spend time with their child after the procedure). Families wishing to participate in the DCDD process need to be aware that the setting will be more clinical and less personal as their child will require continuous invasive monitoring after the withdrawal of interventions. The immediacy of the organ recovery process will limit the amount of time the family will have with their dying child. It is imperative that the medical and transport teams ensure that the child and parents remain their priority throughout this process.¹¹⁴

6.7 POSTMORTEM INVESTIGATIONS

Fetal and perinatal postmortem investigations, or autopsies, are an essential part of caring for families that experience the loss of a fetus or newborn.¹¹⁷ HCPs are responsible for knowing about and explaining the provincial or territorial laws regarding postmortem investigations to the parents. In some provinces and territories, a postmortem investigation is required by law; in others, it is the parent's choice. All parents should be offered the option of a full postmortem examination, even if the cause of the baby's death appears obvious, because additional information may be important for genetic counselling and the parents' decisions about future pregnancies.^{40,92,117} Regardless of the gestational age of the baby, consent is required for any postmortem examinations, tests or investigations.³

When approaching parents for consent, discuss the options for a full, limited or step-wise postmortem examination, as well as the issue of retained fetal tissues, the value of autopsy, and the possibility that the information gained may not only benefit the family but also others. This information needs to be provided with sensitivity, while respecting the personal, cultural and religious values of the family.¹¹⁸

Parents may not choose a postmortem examination of their baby for many reasons. If they do not wish a full autopsy, alternative investigative options (e.g., radiological examination only) can be suggested and their limitations disclosed.¹¹⁷ Some parents may consent to an external examination only; partial examination confined to a specific region of the body; blood or urine test; skin biopsy, needle biopsy and aspiration of body fluids; postmortem imaging; or placental examination.³

A postmortem examination begins with the HCP inspecting the placenta and physically assessing the baby. This informs the health care team and family of the clinical presentation for the remaining postmortem investigation. Postmortem investigations may provide a cause of death or reasons for the pregnancy loss.

REASONS WHY PARENTS MAY NOT WANT A POSTMORTEM INVESTIGATION^{15,118,120}

- They feel that the baby has suffered enough
- They believe that a postmortem examination is not necessary
- They do not want the baby to be *cut open* or *harmed* in any way
- The information a postmortem examination provides may not be of benefit to them
- They are concerned that a postmortem examination may delay the funeral
- They know a postmortem examination will shorten the time they can spend with the baby
- The postmortem examination involves transferring the baby to another hospital or facility
- Postmortem examinations are uncommon in their culture or go against their religious beliefs
- They may have to wait to receive results

For more information about maternal, fetal and placental investigations to determine the cause of a fetal death, refer to the Society of Obstetricians and Gynaecologists of Canada (SOGC) clinical practice guideline *Stillbirth and Bereavement: Guidelines for Stillbirth Investigation*.¹¹⁹ For more information on the approach to perinatal autopsy, refer to the SOGC technical update *Fetal and Perinatal Autopsy in Prenatally Diagnosed Fetal Abnormalities with Normal Karyotype*.¹¹⁷

Giving parents a realistic idea of when the results might be available is important.¹²⁰ Parents should be offered a follow-up appointment with the primary HCP to discuss test or postmortem investigation results, obtain consent for additional testing and offer genetic counselling when appropriate. Such an appointment could also provide an opportunity to plan the management of future pregnancies.

6.8 CREMATION, BURIAL AND FUNERAL AND TISSUE DISPOSAL

Regulations with respect to cremation, burial and tissue disposal differ across provinces and territories. Hospitals must ensure that all remains are handled and treated with respect, regardless of gestation length or circumstances of death.³ HCPs will want to know their institution's policies regarding cremation, burial and tissue disposal, as well as relevant provincial/territorial regulations, in order to have informed conversations with parents.

Before making a decision, parents need to be provided with information about all available burial and cremation options that can be arranged by the hospital or privately. It is important to encourage parents to become involved in the burial plans and arrangements by, for example, referring families to local funeral homes and advising them of any available financial help with funeral costs.

If parents have not decided on cremation, burial or tissue disposal before leaving the hospital or birth centre, they need to be told how long the baby's remains will be stored and what arrangements will be made if they do not make a decision within this timeframe.³

6.9 GETTING READY TO GO HOME

Leaving the hospital or birth centre and going home to baby items and reminders of pregnancy is difficult for grieving families. HCPs can suggest ways that bereaved parents can prepare for these reminders and deal with telling others about what happened and the possible responses.

Prior to the parents leaving the health care facility, inform them of the community and hospital resources they can access, as well as the birth and death registration processes, and provide them with any appointments for follow-up care.

Some families may not be ready to discuss certain issues at discharge. These subjects can be introduced for discussion by their family physician, midwife or community resources in the weeks/months following discharge.⁵⁸ Discharge routines should be flexible and adapted to meet the family's current physical and emotional state.

If the mother has given informed consent, contact her primary care provider on the day of discharge, followed as soon as possible by a detailed discharge letter with a full history of the woman's or baby's care and postmortem examination/test results (if applicable), and information about the condition, follow-up plan, health care services offered, and recommended support services including contact coordinates.





7 FACILITATING AND SUPPORTING GRIEVING IN THE COMMUNITY

A family that experiences a perinatal loss needs access to support and referrals in the community. Because a perinatal loss usually occurs in a health care facility, the parents may return home without the necessary support. It is up to hospital and community HCPs to ensure that families receive follow-up and appropriate support services—all with their informed consent. Both immediate and long-term follow-up care should be made available to all parents who experience a pregnancy or infant loss.³ Depending on the size and nature of the community, support resources may include parents or grandparents, close friends, peer support groups and professionals.

Community support varies by geography and urban versus rural setting. Collaboration between hospitals and community agencies is needed to determine what resources are available in the community and how to make appropriate referrals. Community support is best provided by a team. Team members may include family members, friends, HCPs (e.g., nurses, social workers, physicians, midwives), doulas, clergy, funeral directors, bereavement counsellors and other 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.

Families are to be provided with written information about appropriate sources of continuing support, both professional and voluntary. Bereaved parents who are having trouble coping with their normal day-to-day activities or are experiencing marital problems require a referral to the appropriate consultants.

7.1 FOLLOW-UP CARE

Parents will need follow-up care and support in the community as they go through their grieving process, and an offer of ongoing care (beyond the initial follow-up appointment) should be made to all bereaved parents.³ The care could include listening to their experience and understanding their grief; physical and emotional support; validating the cause of death when postmortem investigations become available; making referrals to specialist services (e.g., genetic counselling), appropriate support organizations/groups or counselling services; and exploring lingering doubts and questions. Family needs will dictate the frequency and schedule of the follow-up care.

Isolated communities often present special challenges for follow-up care. HCPs in larger urban centres may not be aware of the resources and networks available to the family once they return home. Coordination with the woman's primary care provider, local public health agency and local community resources is essential.¹²¹

7.2 RESOURCES FOR PARENTS WHO HAVE LOST A BABY

In recent years, there has been a tremendous growth of media and print resources geared to the needs of bereaved parents. These materials are especially helpful when families have little or no opportunity or inclination to interact directly with other bereaved individuals. For some, reading about grief puts words to feelings. Many find stories about other families who have experienced loss to be the most useful. The personal voice of these stories helps normalize peoples' grief and helps them to give shape and language to their own feelings.

Media and print resources can be made available for loan or reference via the hospital, home, support group or public library. Some organizations, for example, the Pregnancy and Infant Loss (PAIL) Network and Parents Orphelins, provide a resource library for bereaved parents that include recommended readings, suggested perinatal loss support groups and online resources (provincial, national and international) as well as support forums about pregnancy and infant loss.

7.3 BEREAVEMENT SUPPORT GROUPS

Bereavement support groups, which can be facilitated by HCPs or by trained peers, provide support, education and resources in a safe and supportive environment.^{122,123} Different themes are discussed during sessions. Bereavement support programs are delivered in various formats (e.g., open meetings, closed support groups, one-to-one support) and provide a safe space where the bereaved can be heard, accepted and supported through their grief. Regardless of the type of support program offered, confidentiality is critical to enhancing a trusting relationship among group members.

Despite growing evidence on the positive effects of perinatal loss support groups, some communities still lack such services.¹²⁴ However, the Internet has opened a new world of bereavement support that is widely accessible and economical to use. Many individuals feel less isolated in their grief through online resources such as blogs, online chat groups (closed or open), message boards and scheduled online support group meetings. Some people feel freer to talk when they are not visibly emotional and do not have to deal with people's reaction face to face.¹²⁵

TOPICS IN BEREAVEMENT MATERIALS

- Common responses to grief and loss
- Potential differences in expressions of grief (e.g., mother and father)
- Bereavement of family members (e.g., parents, grandparents, siblings, extended family and friends)
- Mother's physical care needs (e.g., vaginal bleeding, breast care, sleep and rest, signs of infection, pain relief instructions, expected recovery trajectory)
- Symptoms and concerns that warrant contacting an HCP (e.g., depression, anxiety or an inability to sleep and eat that last for several weeks)
- Sexuality and communication after a perinatal death
- Paid parental leave and alternatives for fathers (e.g., sick leave)
- Coping strategies
- Community and online resources
- Funeral arrangements and other rituals
- The autopsy, tests and related timing and anticipated results
- Planning a subsequent pregnancy

Most Internet support group users prefer having a group moderator or facilitator with psychological or medical knowledge of pregnancy loss.¹²⁵ The moderator plays a key role in confirming the validity of information shared within the group.¹²⁶ The flexibility, convenience, anonymity and privacy of Internet communication in general and online bereavement support in particular are aspects that bereaved parents appreciate.¹²⁵ Some disadvantages of online support groups include trolling (messages intended to sow discord or controversy), exclusion, watching the suffering of others, difficulty in developing close personal friendships and adoption of a new identity as a griever.¹²⁷

It is important to note that peer support groups do not respond to the needs of all bereaved families. In addition, the timing and access to groups can differ widely. Professional grief counselling may be necessary, and interventions could include individual counselling or facilitated therapy groups staffed by professionals with expertise in bereavement work.

7.4 ANNUAL MEMORIAL SERVICES AND EVENTS

Some health care facilities provide annual memorial services or a burial area to allow group commemoration of pregnancy losses and infant deaths. Bereaved families and HCPs can participate in services or events, which may be held at the health care facility, a local cemetery or elsewhere. Some of the organizations that provide bereavement support services also hold annual acts of remembrance (e.g., awareness walk/run; butterfly release; family picnic; garden vigil; candle-lighting vigil; benefit concert; lighting up a building such as a tower, bridge or tourist attraction).

A supportive community for perinatal grieving can be created by increasing public awareness of the experience of perinatal loss and addressing the stigma that families face. Since 2005, several provinces (New Brunswick, Nova Scotia, Ontario, Manitoba and British Columbia) have declared October 15 *Pregnancy and Infant Loss Awareness Day*. In 2015, Ontario passed the *Pregnancy and Infant Loss Awareness, Research and Care Act*.¹²⁸ This Act, *Bill 141*, requires the provincial Ministry of Health and Long-term Care to conduct research into causes of pregnancy loss and to develop programs for families affected by pregnancy loss and infant death.





8 PREGNANCY AFTER LOSS

Most women who become pregnant after a perinatal loss do so with an awareness that their current pregnancy may not end with a live birth. Worries and concerns about the current pregnancy and its potential outcomes are the hallmark of pregnancy after loss.¹²⁹ One of the most important things that HCPs can offer parents is sensitive support to help them deal with their feelings and worries.¹³⁰ It is imperative that all HCPs know about parents' history so that they can respond sensitively to any anxieties or concerns those parents express and be aware of the potential difficulties and challenges they face, this includes:^{1,131}

- Learning the stories of past pregnancies
- Noting past significant milestones or dates that might trigger anxiety during the current pregnancy
- Recognizing that certain procedures such as ultrasounds and fetal heartbeat auscultation may be stressful for the parents

Bereaved parents are at higher risk of having complex pregnancies after a perinatal loss, and require care for anxiety, depression, fear of attachment or post-traumatic stress disorder (PTSD).^{1,132,133} Some parents may need more intensive support and treatment.¹³²

For some parents, attending a subsequent pregnancy support group may be helpful for processing their new identify. The group helps parents reconstruct meaning in their continued bond and attachment to a deceased baby while creating and sharing a narrative of their fears about attaching to a new unborn baby.¹³⁴

It is important for HCPs to be aware of the range of emotional reactions that parents may have during a subsequent labour and birth. Parents are likely to need additional support and encouragement. Families may have many questions throughout labour and birth that need to be answered thoroughly and as they are asked.





9 EDUCATING AND SUPPORTING HEALTH CARE PROVIDERS

Many types of professionals and lay persons work with individuals and families who have experienced a perinatal loss. These include chaplains/spiritual advisers, social workers, hospital and community nurses, clinical nurse specialists, midwives, physicians, doulas, psychologists, counsellors and other bereaved parents. The people best-equipped to provide skilled and compassionate care are those who know about perinatal bereavement care and are willing to explore care preferences with families.¹³⁵

Providing high quality supportive bereavement care can be stressful as well as demanding. It may be hard for HCPs to know what to say or how to help, or even to sit with a family who is sad or distressed.¹³⁶ Providers are themselves at risk of burnout, compassion fatigue, secondary traumatic stress syndrome or PTSD.¹³⁶⁻¹³⁸

9.1 BEREAVEMENT CARE TRAINING

Both parents and HCPs have identified that bereavement care training is crucial for care providers.^{15,37} Bereavement care training can help HCPs develop communication skills and increase their awareness of the potential needs of bereaved parents. It can also help them feel more confident in the care that they provide and help to reduce their stress.³⁹

HCPs working in NICUs, birthing units, maternal and newborn units, pediatric units and clinics, emergency rooms and recovery rooms need information on the grieving process and the role of providers in supporting individuals and families experiencing or grieving a perinatal loss. Everyone benefits when HCPs are provided with undergraduate or postgraduate training and regular updating in bereavement care.^{15,37}

The PAIL Network is recognized as the leading source of educational resources and materials for professionals who provide services to or care for families who have experienced pregnancy or infant loss. The organization provides a Compassionate Care Workshop, information sessions and resources for HCPs.

Some universities, such as l'Université du Québec en Outaouais, offer undergraduate courses on grief and bereavement. The University's Centre for Studies and Research on Family Intervention has developed and implemented workshops for HCPs in bereavement care.

“ Everyone benefits when HCPs are provided with undergraduate or postgraduate training and regular updating in bereavement care.

Interprofessional certification for the numerous disciplines providing perinatal and pediatric bereavement care is available through the Hospice and Palliative Credentialing Center (HPCC).¹³⁹ The Certified in Perinatal Loss Care (CPLC) credential and the Certified Hospice and Palliative Pediatric Nurse (CHPNN) credential provide opportunities for recognition of expertise in bereavement support and end-of-life care for families.

TOPICS TO COVER IN BEREAVEMENT CARE TRAINING^{3,135}

- Experience of loss and grief in general and the uniqueness of perinatal loss (e.g., reactions of different family members)
- Principles of person- and family-centred care (e.g., individualized and inclusive care, parent-led care, informed choice, shared decision making)
- Different types of perinatal loss and support roles for HCPs
- Care needs of families experiencing pregnancy loss, stillbirth and infant loss
- Communication skills and techniques to deliver difficult and bad news and to communicate sensitively and effectively with bereaved parents
- Practical strategies for supporting bereaved families (e.g., emotional and physical support, memory making, postmortem examination, respectful disposition)
- Importance of ongoing support for bereaved parents and the potential impact of their loss on all subsequent pregnancies
- Parents' feedback on support provided during the grieving period
- Impact of perinatal loss on HCPs as well as self-care strategies and available support options
- Available resources (local, provincial and national) to bereaved families and HCPs

9.2 SUPPORT FOR CAREGIVERS

HCPs who support bereaved parents often require support themselves. The type and amount of support that HCPs require can vary depending on the individual and the situation, and it is important to have different support options available. These may include:^{3,31,36,39,140-147}

- Promotion of self-care and self-awareness strategies
- Instrumental support and breaks and co-creation of rituals for caregivers
- Appropriate workload allocation (e.g., extra staffing when a death occurs; the same staff should not be expected to provide care for all bereaved parents; staff have enough time to spend with bereaved families)
- Structured peer or mentor support (e.g., pair new staff with bereavement support worker or experienced staff) with a culture of checking in with colleagues
- Facilitated opportunities to discuss issues related to pregnancy and infant losses (e.g., interdisciplinary rounds, workshops and discussion groups) and bereavement debriefings
- A perinatal bereavement committee, a community of practice or a network of care providers
- Bereavement counselling services or Employee Assistance Programs (EAP)
- Availability of a perinatal psychologist or clinical ethicist to assist families and HCPs in making end-of-life decisions
- Availability of adequate resources, for example, clear processes and procedures (e.g., storage and disposition of pregnancy tissues/fetal remains, required paperwork); a bereavement checklist or quick reference list on the “dos and don’ts” when supporting bereaved families; list of local funeral homes, etc.

CONCLUSION

Perinatal loss is unlike any other, profoundly affecting parents individually, as a couple and as the family system. For parents, the loss of their baby often represents multiple losses (e.g., loss of self-esteem; loss of a stage of life; failure at parenting; loss of a significant person; loss of a family member; loss of hopes, dreams and expectations for the future).

Perinatal loss and grief is a one-of-a-kind experience, unique to each person. It includes physical, emotional, intellectual, spiritual, social and occupational elements. High quality family-centred bereavement care includes compassion, validation of the loss, open communication, informed choice and individualized care. Compassionate communication, the most important element of bereavement care,

is required during all aspects of care for parents throughout and following loss. Effective care and support is always tailored to meet the individual needs and preferences of bereaved parents—and takes into account their religious and cultural practices—without making assumptions about their wishes and decisions. Health care services and organizations have a critical role in supporting the wellbeing of families experiencing loss at any time during the perinatal care trajectory.

Support and care for families experiencing a perinatal loss can also be emotionally challenging for HCPs, who may themselves need access to support. In addition, everyone benefits if HCPs involved in the care of bereaved families are provided with regular opportunities to develop and update their knowledge and skills.

APPENDIX A—ADDITIONAL RESOURCES

CLINICAL PRACTICE GUIDELINES RELATING TO LOSS AND GRIEF

Canadian Paediatric Society

www.cps.ca/en/documents/authors-auteurs/fetus-and-newborn-committee

Manitoba Health, Seniors and Active Living

www.gov.mb.ca/health/publichealth/phnursingstandards/docs/Prenatal_Evidence_Informed_Care_Pathway.pdf

Society of Obstetricians and Gynaecologists

www.jogc.com/subject/obstetrics

Perinatal Services BC

www.perinataleservicesbc.ca/health-professionals/guidelines-standards/perinatal-maternal-mortality-morbidity-review-process

EMERGENCY DEPARTMENT

Pregnancy and Infant Loss Network—Emergency department best practices

<https://pailnetwork.sunnybrook.ca/healthcare-professionals/best-practices>

Provincial Council for Maternal and Child Health—Early Pregnancy Loss in the Emergency Department

www.pcmch.on.ca/health-care-providers/maternity-care/pcmch-strategies-and-initiatives/early-pregnancy-loss-emergency-department

PREGNANCY AND INFANT LOSS

Pregnancy and Infant Loss Network—Resources for health care and service professionals

<https://pailnetwork.sunnybrook.ca/healthcare-professionals/resources>

Institut national de santé publique du Québec—Décès et deuil périnatal

www.inspq.qc.ca/sites/default/files/documents/information-perinatale/deuil.pdf

PRENATAL EDUCATION

Ontario Prenatal Education—Prenatal Education Key Messages for Ontario

www.ontarioprenataleducation.ca/infant-loss

SUPPORTS AND SERVICES

Alberta Health Services—Resources

<https://myhealth.alberta.ca/after-your-stillbirth/resources>

Health PEI—Pregnancy Loss

www.princeedwardisland.ca/en/information/health-pei/pregnancy-loss

Institut national de santé publique du Québec—Ressources et liens intéressants

www.inspq.qc.ca/information-perinatale/fiches/deces-et-deuil-perinatal#qt-information_perinatale_deuil-ui-tabs3

October 15—Resources

www.october15.ca/support/resources

Perinatal Hospice & Palliative Care—Programs and Support

www.perinatalhospice.org/list-of-programs

Pregnancy and Infant Loss Network—Resource Library: Find Support

<https://pailnetwork.sunnybrook.ca/support-for-families/resource-library>

Provincial Council for Maternal and Child Health—List of Pregnancy Loss Resources for Families and Healthcare Providers

www.pcmch.on.ca/wp-content/uploads/2017/08/PCMCH-Early-Pregnancy-Loss-G-List-of-Pregnancy-Loss-Resources-for-Families-and-Healthcare-Providers_Updated.pdf

APPENDIX B—BIRTH PLAN FOR PREGNANCY LOSS

Name of baby: _____

Diagnosis: _____

Birth Parent's Full Name: _____

Partner's Full Name: _____

Sibling's Names and Ages: _____

Expected Due Date: _____

Induction of Labour Date: _____

SUPPORT PEOPLE EXPECTED TO BE PRESENT AT BIRTH:

Doula: _____

Family Member(s): _____

Photographer: _____

Friend(s): _____

Clergy: _____

Other: _____

NON-PHARMACOLOGICAL PAIN RELIEF TECHNIQUES:

Birth ball Peanut ball Mobility Position changes

Breathing techniques Hydrotherapy: Shower Tub

Music Massage Guided imagery

Other: _____

MEDICAL INTERVENTIONS DESIRED OR NEEDED:

Fetal surveillance: None Intermittent auscultation Electronic fetal monitoring

Pain management: None Narcotics: IM IV PCA Nitrous oxide Epidural

Cervical ripening: None Vaginal prostaglandin Oral prostaglandin

Other: _____

Method of induction: None Amniotomy Oxytocin

Other: _____

Pushing options: Spontaneous Directed Pushing Position: _____

Umbilical cord cutting: Delayed Immediate Cord will be cut by: _____

IN THE INITIAL MOMENTS AFTER THE BABY'S BIRTH, THE PARENTS WOULD LIKE:

Baby to be wrapped in a blanket Parents do not want to hold the baby

Baby to be held immediately by birth parent Baby to be held immediately by partner

Other: _____

COMFORT CARE AFTER BIRTH:

Medication (to promote comfort and ease pain) oxygen skin-to-skin contact

Infant Feeding: breastfeed oral drops of breastmilk formula

Baby to stay in room as long as possible

Nurse to help bathe and dress baby

Organ/tissue donation

Breastmilk donation

Take baby home

Transfer to hospice

MEMORY MAKING:

Photographs

Clothing (e.g., sleeper, hat, booties, mittens, blanket)

Ink footprints or handprints

A mould of a hand or foot

Lock of hair (if available)

Measuring tape

Crib card

ID bracelet

Copy of fetal monitor tracing

Other: _____

SPIRITUAL OR CEREMONIAL NEEDS:

Baptism/Naming ceremony

Blessing/Prayer

Ceremony: _____

Other: _____

POSTPARTUM REQUESTS:

Room away from other new mothers and babies

Keep baby in the room

Other: _____

Additional request: _____

Plans for getting the baby to the funeral home: _____

APPENDIX C—EXAMPLE OF A BEREAVEMENT CHECKLIST

FAMILY PROFILE

Parent Giving Birth's Name: _____

Partner's Name: _____ N/A

Siblings (names & ages): _____ N/A

Other Family Members/Support Persons: _____

Contact Phone Number(s): _____

PREGNANCY HISTORY

Pregnancy History: G ___ P___ T___ P___ A___ L___ EDD (yyyy/mm/dd): _____

Previous Obstetric History: _____

Current Pregnancy History: _____

Assisted Reproductive Technology Used: Yes No Details: _____

Multiple Birth: Yes No

Delivery Notes: _____

INFANT PROFILE

Surname: _____ Given name(s): _____ Sex: _____

Date of birth: _____ Date of death: _____ Gestational age: _____

Corrected age (weeks): _____ Birth weight (grams): _____

Weight at time of death (grams): _____

Inborn: Yes No Outborn: Yes No Where: _____ Age at transfer (days): _____

Apgar Scores: (1) _____ (5) _____ (10) _____ (15) _____ (20) _____

Brief Infant Story (i.e., PTL, PPROM, termination, anomalies, IUFD): _____

Coroner contacted: Yes No N/A By Whom: _____

INTERACTIONS WITH THE BABY

Baby seen by:

Birth parent	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Partner	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Siblings	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Family Members	<input type="checkbox"/> Yes	<input type="checkbox"/> No

Baby touched by:

Birth parent	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Partner	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Siblings	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Family Members	<input type="checkbox"/> Yes	<input type="checkbox"/> No

Baby held by:

Birth parent	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Partner	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Siblings	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Family Members	<input type="checkbox"/> Yes	<input type="checkbox"/> No

Baby dressed by: Birth parent Yes No
Partner Yes No
Siblings Yes No
Family Members Yes No

Baby bathed by: Birth parent Yes No
Partner Yes No
Sibling Yes No
Family Members Yes No

Photos Taken: Yes No
Baptism/Naming ceremony/Blessing: Yes No
Hand/Foot Moulds: Yes No
Hand/Foot Prints: Yes No

Other (describe any interactions that may be helpful for bereavement follow-up):

BEREAVEMENT MEMENTOES BOX

'In Memory Of' card: Yes No
Photograph: Yes No
Lock of hair: Yes No
Hand/Foot Moulds: Yes No
Hand/Foot Prints: Yes No
Clothing
(e.g. gown, blanket, hat, booties): Yes No
Tape Measure: Yes No
ID Band: Yes No
Sympathy card: Yes No
Certificate/Blessing/Ceremony: Yes No

Bereavement Box:

Taken by family: Yes No
Stored: Yes No

VOLUNTEER PHOTOGRAPHER

Referral made: Yes No Date: _____ By whom: _____
Consent Obtained: Yes No By whom: _____
Photos taken (yyyy/mm/dd): _____

BEREAVEMENT CARE

Organ and tissue donation agency contacted: Yes No

Comments: _____

Statement of live birth completed: Yes No

By Whom: _____

Family aware of responsibility for burial/cremation: Yes No

If the baby is less than 20 weeks gestational age, is the family aware of options for burial/cremation: Yes No

Funeral arrangements discussed: Yes No Details: _____

Spiritual/religious care discussed: Yes No Details: _____

Bereavement folder provided: Yes No

Family agrees to receive bereavement follow-up: Yes No

Person(s) to provide bereavement follow-up: _____

Family provided with bereavement support contacts: Yes No Details: _____

IMPORTANT CONTACTS REGARDING LOSS AND FAMILY CARE

Caregivers involved (as applicable)	Name(s)
Staff physician(s)	
Nurses(s)	
Nurse practitioner(s)	
Social worker(s)	
Psychologist	
Chaplain(s)	
Children's Aid Society worker(s)	
Neonatal follow-up	
High-risk obstetrics	
Breastfeeding clinic	
Referring physician	
Family physician/OB/Midwife	
Assisted Reproductive Technology program	
Other:	

FOLLOW-UP

1 Week (yyyy/mm/dd):	By whom:	Call Card
1 month (yyyy/mm/dd):	By whom:	Call Card
6 month (yyyy/mm/dd):	By whom:	Call Card
1 year (yyyy/mm/dd):	By whom:	Call Card

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