

When a Baby Dies in Their First Year of Life (Infant Death)



Pregnancy and
Infant Loss Network

 **Sunnybrook**
PREGNANCY AND
INFANT LOSS NETWORK

When a Baby Dies
in Their First Year of Life
(Infant Death)

"We know it hurts. We're here to help."

To access one of Pregnancy and Infant Loss (PAIL) Network's free peer-led support services please contact us at:

Phone: 1-888-303-PAIL (7245)

E-mail: pailnetwork@sunnybrook.ca

Website: pailnetwork.ca

Who you can call for help

Your Healthcare Team

Public Health or Community Nurse

Please contact the health department in your community.

Your Spiritual Care Provider and/or Elder

Mental Health Support Team

Local Crisis Helpline

About Us

We are a not for profit organization that is dedicated to providing peer support to families* who experience the loss of a pregnancy or death of an infant. We achieve this by educating health and service professionals and offering peer support programs through several channels according to families' needs and preferences. Families may choose to receive peer support by telephone, online, and in-person support groups located in many cities throughout Ontario. All of our support programs are led by trained volunteers who have experienced pregnancy or infant loss first-hand.

PAIL Network is able to offer its services with the support of the Ministry of Health and Long-Term Care, generous donors, and dedicated volunteers. To learn more about our support services or to make a donation, please visit pailnetwork.sunnybrook.ca.

Throughout this booklet, gendered language is sometimes used in explanations or to reference existing research or knowledge. PAIL Network recognizes and supports that people have the right to identify the terminology they would prefer to use in reference to their body and that some medical terms and words incorrectly assume or assign gender. We hope this booklet is useful to all childbearing individuals, regardless of their gender identity or expression.

*PAIL recognizes and supports that families have the right to define themselves and that not all families conform to cisnormative and heteronormative ways of being. PAIL is committed to supporting the diverse needs of all families, including those from 2SLGBTQ communities.

Please Note

While this publication is intended to offer useful information, it is not intended to replace the advice and care of professional healthcare providers.

Thank you

PAIL Network would like to thank Women's College Hospital for their permission to reprint "*The Rights of the Baby*" and "*The Rights of the Parents*".

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Ceilidh Eaton Russell
Dr. Adam Rappaport
Dr. Paige Church
Dr. Sarah Lord
Jodi Ouellette RN, BScN
Lesley Sabourin
Liz Siydock

Dedication

This booklet is dedicated to the memory of the babies whose lives were short, but important, and to the families who love and miss them every day.

Contents

Definitions – words, meanings, and special terms	10
Introduction	12
What to expect from this booklet	12
What is an infant death and what causes them?	15
Medical Information	17
When a baby dies from prematurity	19
When a baby dies from pregnancy or birth complications	21
When a baby has a life-limiting condition	22
When a baby dies from an illness or injury	24
Sudden Unexplained Infant Death	24
Office of the Chief Coroner and Ontario Forensic Pathology Service	25
Family Liaison service	25
Compassionate viewing	26
Next of Kin clinic	26
NICU, Pediatric, Hospice, or Palliative Care Professionals	29
Care for your baby: Comfort-focused care	31
Planning for comfort-focused care: Antenatal diagnosis	32
Questions to ask	34
What professionals want you to know	34
Hospice	36
A note about emergencies	37
Respect for parents and babies	39
For parents	40
For babies	41
Saying goodbye: Memory-making	43
Ideas for memory making	45
Cultural and spiritual traditions	45

Grief and loss: a lifelong journey	47
Does everybody feel this way? Sadness, shock, guilt, and anger	49
Beyond worry and sadness: Anxiety and depression	50
Grief and your relationship	52
Children's grief	53
Special challenges	55
Taking care of yourself	59
Physical healing and follow-up	60
Milk production after loss	61
Emotional support ideas	65
<i>Appendix one</i>	69
Children's grief	69

Definitions

Words, meanings, and special terms

Comfort-focused care

Comfort-focused care is a term sometimes used by professionals to show that even if your baby is not receiving medical care to prolong their life, they will still get care that makes sure the baby is comfortable and keeps you together as a family. Often, the focus of care is on stopping suffering and improving quality of life for as long as your baby is alive. Comfort-focused care is an active approach to care that can be done alongside other types of care or medical interventions. Comfort-focused care can help with bonding, making the time you have together as a family more comfortable, and managing pain and symptoms for your baby. We will talk more about comfort-focused care in this booklet.

Gestational age

Completed weeks of pregnancy measured from the date of a person's last menstrual period. For example, you may hear someone say that *"I am 25 weeks pregnant"*.

Infant death

The death of a baby within the first year of their life.

Neonatal death

The death of a baby within the first 28 days of their life.

Neonatal Intensive Care Unit (NICU)

The NICU is a specialized care unit in a hospital that focuses on giving care to ill or premature newborn infants. The NICU has specialized staff and equipment to help take care of the tiniest and sickest newborn babies.

Prognosis

A prognosis is a term used by medical professionals to talk about the course of an illness or disease, such as whether the symptoms will get better or worse over time, how long a person is expected to live, what their quality of life may be like, and any other problems they may face. Sometimes when a baby is born very early, gets sick, or is found

to have a genetic problem, the medical team may talk about their prognosis with their family.

Stigma

Stigma is often viewed as something negative that changes how people think about or treat something or someone. Often the negative belief is unfair and untrue. Stigma can take away from a person's reputation or mean that a person experiences discrimination because of something negative that is believed to be true about them. Pregnancy and infant loss can carry a lot of stigma.

Stillbirth

In Canada, the birth of a baby who is born without any signs of life at or after 20 weeks of pregnancy or weighing more than 500 grams at birth, if under 20 weeks gestational age. The baby may have died during pregnancy (called intrauterine death), labour, or the birthing process (but before they were born). In this booklet, we will not talk about stillbirth. For more information, please speak to your healthcare provider, or request a copy of PAIL Network's booklet "*Silent Birth: When a Baby Dies After 20 Weeks of Pregnancy (Stillbirth)*".

SUIDS/SIDS

Sudden Unexplained Infant Death Syndrome, also sometimes still called Sudden Infant Death Syndrome, is when a baby dies suddenly or unexpectedly with no clear reason within their first year of life. Often the baby is healthy otherwise, before their death. These deaths often occur during sleep or in the baby's sleep area.

Termination of pregnancy

A medical term that includes both surgical and non-surgical methods of ending a pregnancy. In this booklet, we will not be talking about infant deaths that happen because a pregnancy is stopped or interrupted, either by medication or surgery. For more information on this topic, please speak to your healthcare provider, or request a copy of PAIL Network's booklet "*A Difficult Choice: A Booklet for Families Ending a Pregnancy*".

Viability, and borderline viability (periviability)

'Viability' means an ability to live or survive. When babies are born very premature, a family may hear the healthcare team talking about the risks and complications to their baby, and whether they are too little or early to survive outside the womb. Sometimes the timeframe around these early births is referred to as 'borderline viability' or 'periviability'.

Introduction

What to expect from this booklet

The death of a baby is a tragic and often shocking end to a life, no matter the reason. We are deeply sorry that this has happened to you, and that your baby has died. Bereaved parents and healthcare professionals created this booklet to guide families through what to expect when experiencing the death of an infant. This will be a very difficult time in your life, and we want you to know that there is help and you are not alone.

You may have many questions about what to do around the time of your baby's death. Reading this booklet can answer some of the questions you may have at this time. There are many different reasons why a baby dies within the first year of their life. Although there are other reasons, this booklet covers deaths that happen because of:

- **Prematurity, where a baby is born early and dies because they are too little to survive, or because they have health problems that are related to being born premature**
- **Sudden, unexplained reasons, sometimes described as Sudden Unexplained Infant Death Syndrome (SUIDS) or Sudden Infant Death Syndrome (SIDS)**
- **Health problems that may or may not have been identified during a pregnancy, or started because of pregnancy or birth complications, but that mean that a baby is likely going to have a short life**
- **Health problems that started after birth but that mean the baby will die within their first year of life (for example infection or injury)**

Families will be given this booklet at different times, including during their pregnancy if they know their baby will likely not live for long after birth. However, most families will be given this booklet after their baby has already died. Because of this, **you may find that all sections of the booklet are not relevant to you or helpful. Please read through this booklet in whatever way is useful for you.**

This booklet is intended as an overview of experiences that may occur around the time of the death of your baby. We hope the information in this booklet will help you better understand infant death and ways to find the support you may need.

We hope this booklet helps you understand the following:

- Many parents feel overwhelming and complicated emotions following their baby's death, including shock, sadness, numbness, shame, guilt, anger, and self-blame. If you feel these things, you are not alone.
- Many families feel very isolated and alone after their baby dies. This may be because they don't know many other people who have had this happen, or because after their baby died they did not know where to turn for support. Families may find that everyone is grieving and feeling alone, and struggling to cope, even if they are together in the same house. Overwhelming sadness for everyone in the family can make it hard to connect with and support each other.
- After a baby dies, many families wonder if there is something that they did to cause the death or something they did to cause the baby to be sick or born early. Families may think, "*If only I did...*" or "*If only I didn't do...*" or "*If only I had done...*". Families may have "done everything right", and their baby still died. If you feel or think these things, you are not alone.
- Many infant deaths happen for complicated, sudden, or unknown reasons. At other times, babies are sick or have an underlying medical condition. No matter how or why a baby dies, it never helps to blame yourself. Many families say that even if they are told this, they still blame themselves. If you feel this way, it may help to reach out to your healthcare team or other supports to talk about your feelings of guilt or blame.
- You will have special needs during this time and deserve a care team that is kind, helpful, and supportive. There may be many care and support options offered to you and your family and you should choose what is best for you. Sometimes, what is available close to you will depend on where you live, and you may find online or telephone supports are easiest to access. We will talk about these options further below.

- People experience the death of a baby differently, and there are no right or wrong ways to feel during this time.
- Intense grief is a natural response to the death of a baby.
- The impact of a baby's death stays with a family forever. Although the supports you need will likely change over time, you may find that for the rest of your life you have times where your grief is very strong and times where your grief feels very manageable. This is normal.

What is an infant death
and what causes them?

What is an infant death and what causes them?

In Canada, an infant death is defined as the death of a baby born alive who dies within the first year of their life. When a baby dies after birth within the first 28 days of their life, it is medically called a neonatal death.

Worldwide, it is estimated by the World Health Organization that approximately 4.1 million babies die within their first year of life. In Canada, we know that at least 5 babies die within their first year of life every day. That represents one baby, one family, every 5 hours. In Canada most infants die from four main causes:

- **Being born too early (prematurity)**
- **Genetic or health problems or conditions that exist during pregnancy or at birth (e.g. anomalies or genetic problems)**
- **Pregnancy or birth complications (e.g. bleeding, lack of oxygen)**
- **Sudden Unexplained Infant Death Syndrome (SUIDS)**

Medical Information

Medical Information

Below we will talk about some ways that babies can die, and how families may feel or experience things in different ways. Although each situation and each person's experience is unique in many ways, there are some things that can be challenging when a baby dies, regardless of how it happens. A family may:

- Be shocked that things like this can happen. Everything may be going well, and then suddenly it is not. A family's future hopes and dreams can suddenly change from what they had previously expected and this can be devastating.
- Experience a lot of uncertainty, and find that professionals do not know all the answers or what will happen. During this time, uncertainty is normal, and families tell us that it is often very hard to make decisions when you may not have clear answers or know what the future will bring. A family may never get the answers they are looking for.
- Feel shame about what is happening. They may feel that their pregnancy, their own of their baby's body is out of their control, and feel upset when they hear people complain about their own pregnancies or babies that seem 'easy'.
- Hear stories about 'miracles' or other babies in similar situations that survived, and wonder why their baby didn't. They may always wonder if they made the best decision for their baby and their family.
- Be separated right after birth, either at the same hospital or at different hospitals, if the baby needs to be moved. They may feel like they lost precious time to be together, when time was so short.
- Be far away from home, or from friends and family. When a baby or family has been cared for away from their home, they may find that when they return home, no one knows what happened or that their baby died. This can mean a family feels even more alone and isolated.

- Feel anger towards the healthcare system or healthcare professionals, especially if they feel that not enough was done to help their baby, or if they feel they weren't listened to when they looked for help.
- Feel shame or guilt and question everything about what happened and whether anything could have been different.
- Feel extreme distress when returning home to where they have lived with, or prepared to live with their baby. Their belongings are there, as well as shared memories or hopes and plans.
- Feel traumatized by the whole process that happens when a baby dies. They may feel those feelings rush back any time they see a hospital or a baby or person who is pregnant or hear an ambulance, fire truck, or police car.
- Be forced to go back to work soon after their baby has died, especially if their benefits stop after their baby's death, and they need to return to work to keep their job or make money.
- Find that people ask nosy or insensitive questions about what happened.
- Feel that there are very little supports for families, and very few people who understand this type of loss.

When a baby dies from prematurity

Sometimes, a baby dies because they are born very early in a pregnancy. A full-term pregnancy is 9 months, or 37-40 weeks gestation. If a baby is born before 37 weeks gestational age, the birth is described as pre-term or premature. Sometimes, babies are born much earlier in a pregnancy. Babies that are born between 20 and 26 weeks gestation are sometimes described as being born during a 'perivable' time, meaning that they are at high risk of death or other long-term issues if they survive. Around this time, you may also hear the medical words 'premature', 'pre-viability', or 'borderline viability'.

When a baby is born very early in a pregnancy, they may not be able to survive, or if they were to survive, they may have many health problems or complications. Sometimes, the health team will explain

to a family that a baby will die because they are too premature to receive life-prolonging interventions, such as help with breathing. This is most common when a baby is born before 23 weeks gestational age. Sometimes, the healthcare team will explain to a family that attempts at certain life-prolonging interventions are possible but that if their baby survives they may have some major medical problems. In this scenario, a family may make a difficult choice to not have interventions to prolong their life, but to provide comfort-focused care to their baby until they die. This may happen for babies that are born around 23-26 weeks gestational age, although it is most common for babies born at 23 or 24 weeks gestational age.

At other times, attempts at life-prolonging interventions for a baby do not go as hoped, or there are complications that mean that a baby dies shortly after birth, or a while later in a hospital. In some situations, a family may make a decision to provide comfort-focused care until their baby passes away.

Special challenges

There are some things that make having a baby born very early very challenging. A family may:

- Hear words or language that make them feel guilty or ashamed. They may hear words, such as ‘incompetent cervix’, that make people wonder why their body ‘failed’ to hold a pregnancy, or be asked why they didn’t come in sooner to be checked. This may make people feel like their baby’s death is somehow their fault.
- Find out that something is wrong and their baby may be born and die in an urgent situation, such as if their water breaks or they have contractions and the birth happens very quickly. A family may have to make fast decisions and may wonder if they made the right decisions. An urgent situation may feel like it comes out of nowhere, where everything is fine, and then it isn’t.
- Be in the hospital for a long time or sent to a hospital away from their home community, and have long hours or days waiting to know what will happen. During a pregnancy, they may have to wait at home until they get further along in the pregnancy, and have many unknowns.
- Have to make difficult decisions about watching the baby’s heartbeat in a pregnancy or having a c-section or not. They may

be scared to look every time they go to the bathroom or every time their temperature is taken, in case there is blood or a fever.

- Have a lot of uncertainty, especially at the time of their baby's birth. It is important for you to get the information you need. During this time, uncertainty is normal, and families tell us that it is often very hard to make decisions when you may not have clear answers or know what the future will bring. A family may never get the answers they need or want.
- Do everything 'right', but their baby is still born early.
- Be separated at birth, especially if their baby needs to be moved to a different unit or hospital. When a baby's life is so short, it may feel unfair that some of that time was spent away from each other.

When a baby dies from pregnancy or birth complications

Sometimes a pregnancy or birth does not go as expected, and a baby dies from complications after they are born. For example, this may happen because a baby did not have enough oxygen at some point or because of too much bleeding. Sometimes, a family will know soon after birth that their baby will die, while other families will find out much later after medical interventions are not working. When this happens, after talking to their care team, a family may be faced with the difficult decision to not have more interventions to prolong their life, but to provide comfort-focused care to their baby until they die.

Special challenges

There are some things that make having a pregnancy or birth end with complications especially challenging. A family may:

- Hear words or language that make them feel guilty or ashamed. They may be asked why they didn't come in sooner to be checked, or why they didn't know that something was wrong. This may make people feel like the loss is somehow their fault. They may also hear words that they don't understand or medical terms that seem harsh or to lack sensitivity.
- Find out that something is wrong and their baby may be born and die in an urgent situation, such as if they have sudden bleeding or

the baby's heartbeat is low and the birth happens very quickly. A family may have to make fast decisions and may wonder if they made the right decisions. An urgent situation may feel like it comes out of nowhere, where everything is fine, and then it isn't.

- Have a lot of uncertainty, and find that professionals do not know all the answers or what will happen. During this time, uncertainty is normal, and families tell us that it is often very hard to make decisions when you may not have clear answers or know what the future will bring. A family may never get the answers they are looking for.
- Do everything 'right', or have no known risk factors, but there are still complications.
- Distrust healthcare professionals, especially if they feel like they are somehow to blame for what happened.
- Feel abandoned or isolated, especially if they feel that the professionals who were there during the pregnancy or birth are avoiding them or unavailable to meet to talk about what happened.

When a baby has a life-limiting condition

Sometimes a baby dies because they have a condition or diagnosis that is potentially life-limiting. A life-limiting condition means that a cure is very unlikely and that the condition will likely lead to a shortened life span. For example, a family may find out that their baby has a complex genetic condition or a problem with a body part (heart, brain) that means they likely will not live for long. Sometimes, a family will find out that their baby has a potentially life-limiting diagnosis during a pregnancy, because of a test result that is received, or because of findings from an ultrasound. At other times, a family will find out that their baby has a potentially life-limiting diagnosis after they are born.

Special challenges

There are many things that make having a baby with a potentially life-limiting diagnosis especially challenging. A family may:

- Be shocked that they need to talk about end-of-life care, or that this is something they have to think about. A family may hear devastating news during an ultrasound, or have birth complications

that mean their otherwise ‘normal’ pregnancy will be forever changed. A family may have a baby that is sick and bring them to the hospital for care, only to hear the news that their baby will die.

- Find out that their baby may have a life-limiting diagnosis during a pregnancy, and have days or months to wait until birth, with uncertainty about what will exactly happen, and when.
- Have many tests and appointments and have to meet many different professionals. They may have to repeat their story over and over again. They may have to travel away from home for this care.
- They may have to explain often why they are choosing to continue or end the pregnancy and feel that people are pressuring them to make a different decision.
- Have to make hard decisions about tests, screens, and what to do or not do. They may have to wait for test results and explanations and may wonder if they made the right decisions.
- Have to make decisions about where the death will happen. Some families will stay in a hospital, while others will have access to a hospice setting. Other families will be at home, with support from professionals. Sometimes what is available to you depends on where you live. At other times, you will be asked about what you want to do. Families say that knowing what to do, when you have a choice, is difficult.
- Face questions from people who don’t know what is happening, such as whether they are excited about their birth or when they will be ready to bring the baby home. They may find it hard to do things that other pregnant people may normally do, such as having a gender reveal, baby shower, and preparing the baby’s room.
- Not know about the timelines, for example how long the baby will live. Not knowing this can be very distressing for families. They may not know how long they need to be away from home, or how long they need to arrange care for other children or pets, or if their baby will be able to be home with them for some time.

When a baby dies from an illness or injury

Sometimes a baby that has been healthy otherwise dies unexpectedly, after getting sick or after an injury. A baby may die at home, or in the hospital after going there urgently for treatment or care.

Special challenges

There are many things that make having a baby die from an illness or injury especially challenging. A family may:

- Worry that an illness could spread to other family members, including other children in the home.
- In the time around an injury, feel like they are treated by the system and professionals as if they are at fault, or as if they did something to cause their baby to die. They may be questioned by police and other professionals and have to answer questions that seem unfair and cruel at a time where they want to be with their child. A family may also feel a lot of guilt or feel like they may have been able to do something to prevent the death.
- Be separated from their baby at the time of their death, as well as other family members and friends.
- Feel extreme distress when returning home to where they have lived with their baby. All their belongings are there, and there are many shared memories.

Sudden Unexplained Infant Death

Sometimes a baby dies suddenly or unexpectedly after they have been healthy or well at home. Although it can happen anywhere, for many families their baby will die during sleep or in their sleeping area. Even when a family does everything they can to lower the chance of their baby dying from SUIDS, it can still happen.

Special challenges

There are some things that make having a baby die from SUIDS especially challenging. A family may:

- Feel like they are treated by the system and professionals as if they are to blame, or as if they did something to cause their baby to die.

They may be questioned by police and other professionals and have to answer questions that seem unfair and cruel.

- Be separated from their baby at the time of their death, and other family members and friends.
- Have some of their baby's belongings taken, and be told they cannot return to their home right after their baby died. They may have to wait until there is an investigation, and find another place to stay until it is done.
- Never get a final cause of death, and struggle to have follow-up and information from the professionals involved.
- Feel traumatized by the whole process that happens when a baby dies from SUIDS. They may feel those feelings or images rush back any time they see or hear an ambulance, fire truck, or police car or in other unexpected situations.
- Ask themselves, "*Why?*" or "*What could I have done differently?*"
- Worry about other children or other babies born after, that the same thing could happen to them too.

Office of the Chief Coroner and Ontario Forensic Pathology Service

Family Liaison service

When there is an investigation into a baby's sudden unexpected death, all families in Ontario can access the **Family Liaison** service through the Office of the Chief Coroner (OCC) and the Ontario Forensic Pathology Service (OFPS). Some of the services provided are only at the Toronto Office and a few of the Regional Offices, but everyone can call and ask about what is available for them. You can ask your healthcare team to support you in starting this service for you, or call yourself. The coroner who is involved in your child's investigation or the police service may also be able to connect a family to this service. Even if a coroner is not sure if this service is available to you, you or a family member can still call the Office of the Chief Coroner, and they will help you to see what is possible. In your community, a healthcare professional may not be aware of this service, so it will not be offered to you. You can always call the Office of the Chief Coroner to ask

yourself. Through the Family Liaison service, families may be able to get help with:

- Follow up with the coroner's investigation, including information about what happened.
- Help with understanding medical reports, such as the pathology/autopsy or genetic reports, in language that is easier to understand.
- Getting reports from the OCC/OFPS related to your child's death. You will need to sign an authorization form to release the reports.
- Direction for financial assistance to bury/cremate your child.
- Grief support resources.

Compassionate viewing

At times where there may be a delay in you seeing your baby, you may be able to arrange something called a "***compassionate viewing***".

- This is a time for you to see and sometimes hold or touch your baby.
- Professionals who work with families during this time feel it is best to only have the closest and most trusted people with you during this time, as it is a very intimate experience. Sometimes, you may not be able to hold or touch your baby, and the viewing may be done through a window. The team will help you understand what you will see beforehand and answer any questions you have.
- Depending on where you live, you may or may not be able to access a compassionate viewing. If this is something you want to ask about, you can contact the Office of the Chief Coroner, and they will be able to talk to you and give you contact information for local services, if they are available.

Next of Kin clinic

If you have questions about your baby's death and would like to speak with the Investigating Coroner (doctor looking into the baby's death), the Forensic Pathologist (doctor determining the cause of your baby's death through an autopsy), the Police Service, and/or a hospital representative, arrangements can be made for a ***Next of Kin Clinic***. All families in Ontario can request this, and it will be arranged through the Office of the Chief Coroner. You or a family member may call the Office of the Chief Coroner to request this service.

- This is an opportunity for you to meet face to face with people who have been involved in the care of your baby at the time of their death.
- You will be asked to create a list of questions/concerns you have regarding the death investigation or the police investigation. Your questions are very important to inform the team about your concerns and to direct the meeting.
- The meeting usually lasts around 2 hours and if a follow up meeting is necessary for additional questions another will be booked.
- The OCC/OFPS may also contact you to request you attend a Next of Kin Clinic meeting because they want to share results from tests with you, such as genetics, toxicology, histology or serology.
- It is important to know that the meeting with the OCC/OFPS can happen at any time. For example, this can happen soon after the death of your baby, or even 1,2 or 5 years later.
- For some people, meeting with the team involved in the death investigation and asking questions can all be a part of healthy grieving. For others, this may feel like “too much”. You can decide what is right for you.

NICU, Pediatric, Hospice, or
Palliative Care Professionals

NICU, Pediatric, Hospice, or Palliative Care Professionals

You will likely meet many different professionals who are caring for you and your baby. These professionals are able to provide care, support, and monitoring for babies when they are alive and surrounding their deaths, and care and support for the whole family during this time. Some professionals will also be involved in your care because the usual staff caring for your baby has asked for their help. Depending on where you give birth, and the circumstances around your baby's death, you may meet professionals at home, in a hospital, or in a hospice or other community setting.

Some professionals you may meet during this time include:

- Nurses
- Neonatologists or pediatricians (doctors who care for babies)
- Social workers
- Lactation consultants (help with breast/chest feeding)
- Spiritual care providers
- Peer support providers
- Grief support coordinators
- Respiratory therapists (help with breathing)
- Family doctors
- Dietitians
- Sonographers (ultrasound professionals)
- Psychologists or other mental health professionals
- Maternal fetal medicine doctors (doctors who care for people with high risk pregnancies or pregnancies where the fetus has a complication or medical condition)
- Obstetricians or Gynecologists (doctors who specialize in pregnancy, birth, and reproductive health)
- Genetic counsellors

Care for your baby:
Comfort-focused care

Care for your baby: Comfort-focused care

Professionals will continue to provide care to your baby when it is known they will die, and the plan is to stop or avoid medical interventions that are not felt to be helpful for prolonging your baby's life. During this time, you may hear the words 'palliative care', 'comfort-focused care', 'end of life care' or 'withdrawing life support' used by the healthcare team. Many professionals use the term 'comfort-focused care' now. Comfort-focused care is a term sometimes used by professionals to show that even if your baby is not receiving medical care to prolong their life, they will still get care that makes sure the baby is comfortable and keeps you together as a family. Often, the focus of care is on stopping suffering and improving quality of life for as long as your baby is alive. Comfort-focused care may be the first plan, such as when a baby is born at 21 weeks and too little to have other medical interventions, or a decision a medical team and family make when it is known that other medical interventions are no longer the best course. This specialized support is given at different times, depending on when it is discovered or decided that a baby will need this type of care. Your baby may receive comfort-focused care in a hospital, hospice, or at home. Some aspects of comfort-focused care, such as treating pain, can also be done while a baby who is medically fragile is still receiving some life-prolonging interventions.

Planning for comfort-focused care: Antenatal diagnosis

Sometimes, a family will know during a pregnancy that their baby will likely not live for a long time because a life-limiting diagnosis or condition is suspected. At this time, a family may have the option to meet with a special care team to discuss their hopes and wishes for the pregnancy and their baby's life. This care team may be in a hospital, in a hospice, or in the community. Some words you may hear to describe this special care team may be a 'palliative care team' or 'hospice care team' or 'quality of life team' or 'pediatric advanced care team (PACT)'. In this booklet, we will refer to this special care team as a palliative care team.

Professionals who provide care for babies and families during this time have shared some information that you may find helpful to know, including:

- Many families will be connected with the palliative care team by other people in their healthcare team. Other families will make this connection themselves.
- Even if a family isn't sure if they would like to choose comfort-focused care for their baby, it may still be helpful to meet with the palliative care team to talk about their options and then make the decision about what is best for them and their baby. Some families who receive a baby's life-limiting diagnosis during pregnancy may look into comfort-focused care if they would like to continue their pregnancy for as long as possible after their baby's diagnosis. Other families will decide to stop their pregnancy (medically called a "termination of pregnancy").
- The possible services and options for care may depend on where you live and what is available in your community. It may also depend on how far along you are in your pregnancy and what type of diagnosis your baby has.
- When a family meets with the team, they will discuss their baby's diagnosis or condition, their prognosis, their hopes for the pregnancy and their baby's life, and their plan for support during the pregnancy (if the baby isn't already born) and their baby's potential death.
- The care team will be able to support families through all the difficult decisions they may have to make and help families to make sure the plan of care follows their goals and the medical options available.
- Many times there will be uncertainty. This may be for the baby's diagnosis, for testing, for how long the pregnancy will continue, and for whether the baby will be born alive. The team helps families understand and plan for many different scenarios, but they will likely talk about how we can never be sure, and that we don't always know what will happen. This can be very difficult for many families.
- It may be hard for professionals to estimate how long a baby will live. Having this uncertainty can be very hard for families. The care team will be able to talk about this with you, and to help you understand the different things that are possible or likely to happen. You will be able to ask questions and talk about your fears and hopes.

- Some families will be offered support for birth planning, and support at medical appointments. They may also have support from the team during labour or birth. Families may be connected to different members of the team, such as social workers, spiritual care providers, or nurses. The medical team may also help to coordinate memory making (for example, taking pictures), and to provide information or education. They may also be able to connect you with another family that has been through this before.
- Sometimes a family will meet with the team many times throughout a pregnancy, and at other times there is only one meeting, where a plan is made.

Questions to ask

Professionals who care for families around this time wanted you to know that no question is too simple or silly to ask. Many times, families need to hear the same information over and over again or have time to ask the same questions for clarification. It is important that you have a good understanding of what is happening so that you have the information you need to make difficult decisions. Some questions you may want to ask the healthcare team include:

- **What will my baby look like when they are born?**
- **How long are they expected to live? What if they live for longer? Shorter?**
- **What options do we have for where our baby will be cared for?**
- **What type of care will my baby get? What is possible and why?**
- **Will my baby feel any pain or suffer because of their condition or diagnosis?**
- **Is there a limit to who is able to be with us in the room?**
- **What professionals will be around?**
- **What supports are available after in case my baby dies? For me/my partner or for my other children?**

What professionals want you to know

When a family makes the decision to provide comfort-focused care to their baby, they may still have many questions. It is important that you have your questions answered, and that you feel well supported by your healthcare team. Your healthcare team will answer your questions, and repeat information if you ask them to.

Professionals who provide care for babies and families during this time have shared some information that you may find helpful to know, including:

- Medicine may be offered to you for your baby, so that they do not feel pain and they do not suffer. Suffering is one of the biggest fears that families have for their babies. If this is something you are worried about, please talk to your healthcare team. Your healthcare team will help you to understand if a medication is helpful or needed, or other ways to provide comfort to your baby.
- Many families will want to hold their babies, but this can also feel distressing and scary for some people. Your healthcare team will be able to support you if you feel this is something you would like to do. Families may worry that their baby is suffering when they are holding them, but this is generally not true. If you are ever worried, speak to your healthcare team and they will help you and look closely at your baby.
- There is often a lot of uncertainty at this time and many families say this is really hard. Families are often planning for many situations and professionals will do their best to answer your questions, but many times they will not know the exact answer either, such as how long your baby will live. Babies have their own timelines. Even if a professional has cared for another baby with a similar diagnosis or issue, each baby is unique so they may not be able to predict exactly how or when things will happen.
- It can be distressing if timelines, such as when a baby will die, are not known or followed. It can be overwhelming to think about all the possible scenarios. When a baby dies sooner than expected, it can be devastating. When a baby lives longer than expected, it can be very difficult as well.
- Often a baby's heart is quite strong, and it may be the last thing to stop working. Even when their bodies are shutting down, a baby's heart may keep beating for a while before stopping, even with no other medical help. How often a professional will check your baby for a heartbeat will vary.
- Sometimes the tubes, wires, and equipment (if any) may be able to be taken off your baby, while at other times it may need to stay on. Many families worry that if they are removed, this means that their

baby is not being watched closely. Even if equipment is removed, your care team is still closely watching, and able to use other signs that the baby shows to know how they are doing, for example their facial expressions and breathing patterns. Your healthcare team will be able to answer your questions and explain things to you. If you are ever worried, tell your healthcare team.

- There is generally no reason for you to be separated from your baby during this time. If you want to create a special ceremony, or for a religious or spiritual care provider or other important person to be present, they can very often come to you. Your healthcare team will be able to help you plan.
- If you would like, it is usually okay for family and friends to visit and spend time with your baby. It is also okay if you prefer this to be a private time.
- Many places will offer memory-making opportunities if you would like, such as photos. We will talk more about this below. Making memories, or bonding with your baby, can be very difficult during this time, as you are also experiencing grief. Families have shared with us that even though memory making was very difficult to do, they appreciate these items very much later on.
- You have a right to ask to review what happened and to have your questions answered with a senior doctor. This may happen soon after your baby dies or a while later in a separate meeting.
- No matter how long a baby lives, their short life is important and meaningful. Your team will do whatever they can to help you make the most of every moment you have together.

Hospice

Hospice care is a type of care provided by professionals who have special skills to support babies while they are still alive, and around the time of their deaths, and their families. Depending on where you live, you and your baby may have access to hospice care in a hospital or a hospice building in a community. In this section, we will talk about hospice care professionals, and hospice care.

Professionals who work in hospice have shared some information that you may find helpful if you access to hospice services at any point in your baby's life, including:

- The team will work your family to talk about all the possible options, including what type of care is available, where the services can be offered, and what your hopes are for your baby's life.
- Many hospices have room for other family members and friends, while still offering privacy for families when needed.
- Hospices are still medical facilities, meaning that your baby will still receive the care and support they need from professionals who will watch them closely. Your healthcare team will work together with you to provide care for your baby based on your goals, values, and beliefs. The care team will monitor your baby for pain.
- The care team can help you with bonding, memory making, and support for any special ceremonies you wish you create. We talk more about memory making later in the booklet.

A note about emergencies

Sometimes there are emergencies surrounding a baby's death. This may be because a family comes into the hospital with a pregnancy concern and then the baby is born unexpectedly and dies. Sometimes there is an injury or other emergency that happens and a baby dies. Other times a baby dies suddenly for an unknown reason, such as from SUIDs.

If the baby's death happens around the time of their birth, sometimes the person who gave birth is very ill and in hospital and the other family members are left to cope with the baby's death and the fact that their loved one is also very ill. Sometimes an ambulance is called, and babies are separated from their parents and family. Sometimes there is also a police investigation. Coping with an emergency situation or other traumatic events on top of the baby's death can be extremely difficult. You may feel shock, anger, sadness, numbness, or extreme distress. It is normal to feel these things.

Ask your healthcare team to help you and your family during this time. It may be helpful to remember:

- If there has been an emergency, often there is no rush to make decisions about seeing and holding your baby, making special keepsakes, or funeral arrangements. You can take your time to make some of these plans until everyone is together. It is possible and natural to make memories after your baby has died, and many families will choose to do this. The healthcare team can assist you and your family when you are ready.
- It may help to have a follow-up meeting about what happened, as you may have a hard time remembering and may have new questions. Sometimes families are able to get their questions answered before they go home, while others will ask for an appointment later on to talk about what happened. You can ask your care team to have this meeting with you, even if it is not offered. For families who have a coroner investigation happening, they may be able to request a “next of kin” clinic meeting through the Office of the Chief Coroner (please see section above for more details).
- For families who have a baby die from an injury, crime, or suddenly or unexpectedly, you may be able to access support for you and your family through Victim Services. The police or your healthcare team may be able to make the connection for you, or you or a family member may call directly.
- How you feel about things and the support you need may change over time. At first, you may be in shock and just want to go home. Later on, you may find that you are really struggling with everything that happened and wondering what to do. You may have nightmares or constantly wonder ‘what if’, or ‘if only’. There is help during this time, but you or a loved one may need to reach out and ask for it. This can be extremely difficult for many families. Also, depending on where you live, some supports may be harder to find or access. Talk to your healthcare team, as they may be able to connect you to supports.

Respect for parents
and babies

Respect for parents and babies

In 1984, a group of healthcare providers and families put together a list of important ways to show respect for parents and babies, which are below.

For parents

To see, touch, hold, and nurture their child with no limitation as to time or frequency.

- To be fully informed about the baby, the cause of death, and the process of legitimizing the death (e.g. the funeral).
- To have written and verbal information about:
 - 1) Options available for the burial or funeral
 - 2) Supports available to family members
 - 3) Necessary legal information (e.g. timing of burial, birth registration)
- To receive mementos of their baby (e.g. footprints, picture, certificate of life).
- To acknowledge the life and death of their child, a person in their family.
- To choose any type of burial, cremation, or other funeral service.
- To be heard and listened to by caring professionals, without judgment or prejudice.
- To be cared for by staff who are empathetic, caring, and sensitive to individual responses, behaviour, and choices.
- To be treated with respect and dignity.
- To have the support of family and/or friends at any time, if the parent wishes.
- To seek religious or cultural support for their choices and to be treated with cultural and religious sensitivity.
- To be aware of the grieving process, to be able to grieve openly or quietly, and to be informed of, and understand, the feelings and emotions generated by loss.
- To understand their future options regarding autopsy and genetic counselling
- To be informed about parent support groups.
- To receive follow-up supportive care (at the hospital, primary care practitioner's office, and/or home) by telephone or by visit.
- To have the opportunity to evaluate their hospital and community experience.

Adapted from Women's College Hospital, Rights of parents at the hospital: At the time of the baby's death. Toronto: Women's College Hospital, 1984.

For babies

- To be acknowledged by name and sex.
- To be treated with respect and dignity.
- To be with the grieving family whenever possible.
- To be recognized as a person who has lived and who has died.
- To be remembered with specific mementos (footprints, handprints, pictures, clothes, name band, ultrasound picture).
- To be nurtured (bathed, dressed, wrapped).
- To be buried or cremated.
- To be remembered.

Women's College Hospital, Toronto, 1984.

Source: Health Canada, 1999 Family-Centred Maternity and Newborn Care, Pg. 8.7.

Saying goodbye:
Memory-making

Saying goodbye: Memory-making

Your care team may talk with you about making memories with your baby. Memory-making can happen during your pregnancy, after your baby is born, and after death. It can be really hard to think about bonding with your baby or making memories during this time. If you feel this way, you are not alone.

Professionals who support families wanted you to know:

- Some families may feel at first that the idea of memory-making or bonding is really strange or wrong. A family may feel scared to get attached, or too sad to think about this. There is no right or wrong way to act or feel during this time.
- Many families say that although it can be hard, they are glad they took time to remember their pregnancy and baby. Research has shown that having physical reminders of your baby (photos, handprints, etc.) can be helpful for people who are grieving.
- Sometimes, the decision to do this or not is based on a family's religious, cultural, or spiritual beliefs or values. It may help to talk to your healthcare team, religious, or cultural leaders during this time. Some families will want to stick to traditions and others will not, or will start new traditions. Many families will do a combination of things.
- You may want to include other family members or friends in the process, such as in photos. If you have other children, ask your healthcare team to help you to talk to them about being involved in memory-making activities, both around the time of their sibling's death and later on.
- It's okay to feel both sadness and joy, and many families will feel a mix of emotions.
- You have the right to enjoy your pregnancy and the time you have to bond with your baby, and to make memories during this time. Many families will want to focus on special moments, such as picking a name, focusing on kicks, and doing things they enjoy 'together' as a family. It is also understandable and okay not to enjoy your pregnancy or focus on these things. There is no right or wrong way to feel.
- Sometimes, a funeral home may also be able to assist with memory making ideas.

Ideas for memory making

- Holding, snuggling, and kissing your baby
- Giving your baby a bath
- Taking photographs
- Making hand and foot prints or molds
- Reading and singing to your baby
- Having a special ceremony
- Having friends and family visit
- Dressing your baby
- Going for a walk with your baby, or taking them outside
- Collecting special items, such as a bassinet card, lock of hair, tape measure to show baby's size, clothing or blanket, ultrasound picture, cards, heart beat recording, etc.

Cultural and spiritual traditions

You may choose to have other people, such as siblings, grandparents, special friends, or community members come to see and hold your baby before or after they have died. Some families will want to keep cultural traditions or have a special ceremony together, such as a baptism, cedar bath, or reading. Depending on the type of ceremony, it can take place now, or in the future when you are ready. Your care team can support you through these decisions and help to make arrangements with the hospital, hospice, spiritual care providers, funeral home, and your community leaders.

Grief and loss:
a lifelong journey

Grief and loss: a lifelong journey

When a baby dies, families grieve the loss of their baby and the future they imagined. After your baby dies, you may feel deep physical and emotional pain. We are sorry this has happened.

Grief is a natural, healthy, and loving response to the loss of someone you care about. Grief is deeply personal, which means that everybody grieves differently. Some people move through it more easily, while others are deeply affected. After your baby dies, there is no right or wrong way to feel or grieve.

Grief in some form will likely be with you forever, but many families say that it changes over time. It may feel stronger again at certain times, like the baby's due date, birthday or anniversaries, when standing in the baby's room, holding the baby's toys or clothes, or seeing another pregnancy person, healthy baby, or family with children. It may help to think of grief as a wave, which can come and go. Over time, the waves may start to be farther apart, but when they return, they can also make you feel like you're going backwards. Feeling grief more strongly at different times is normal. It does not mean that you are going backwards or doing something wrong.

The following may be experienced after a baby dies:

- **Crying and sadness.**
- **Not feeling like yourself or like doing the things you normally do or enjoy.**
- **Avoidance of (staying away from) social activities.**
- **Intrusive thoughts, including feelings of guilt and shame.**
- **Feelings of yearning, numbness, shock, or anger.**
- **Feelings of isolation or being alone even if you have people around you.**
- **Feelings of anger, sadness, or confusion about your personal cultural, spiritual, religious, or philosophical beliefs.**
- **A loss of the feeling of being in control or belief that there is 'good' in the world.**
- **Asking yourself, "Why did this happen?" or "What could I have done differently?"**

We know the time right after a baby's death can be very challenging for families. You are not alone in feeling or thinking these things.

Does everybody feel this way? Sadness, shock, guilt, and anger

After a baby dies, many families experience feelings of sadness, shock, anger, and guilt. Sometimes these feelings are connected to a certain event, such as when you are thinking about the baby, when you return to work, when your body leaks milk, on your baby's birthday, or at the start of each school year. Sometimes these feelings seem to come out of nowhere and surprise you when you least expect it.

Many people feel guilty about their baby's death and constantly wonder 'what if' or 'if only'. Some people think a lot about what they could or should have done differently, even if they are told by healthcare providers that it was not their fault. Some people are angry that other people have healthy babies or pregnancies or feel very sad when they know that it was the last time they could 'try' for a baby. Other people feel 'numb' after their baby dies. If you feel or think these things, you are not alone.

We know that far too often, families feel alone and misunderstood by family members, friends, co-workers, and care professionals. You deserve to have the support you need. If you need support, talk to a trusted person, including your care provider. You might also consider supports from a:

- **Social Worker**
- **Psychologist, Psychotherapist, Psychiatrist, or other Mental Health Professional**
- **Public Health Nurse or Community Health Nurse**
- **Community or Friendship Centre**
- **Spiritual or Religious Care Provider, Community Leader, or Elder**
- **Lactation Consultant**
- **Crisis Support Volunteer or Victim Services Volunteer**
- **Palliative care or hospice organization**
- **Online peer support community**
- **Grief support coordinator**
- **Peer support organization such as PAIL Network. You can self-refer by filling out the intake form at pailnetwork.ca**

Beyond worry and sadness: Anxiety and depression

After a baby dies, it is normal for people to have thoughts and feelings that range from sad and angry to shocked and numb. Many of these thoughts and feelings come from grief, which we know is very common for families who have experienced an infant death. **Grief is not an illness.**

Sometimes, certain thoughts and feelings can be a sign of mental health problems such as anxiety or depression. Having anxiety or depression means more than having a bad day or a scary thought. Anxiety and depression can happen to anyone. Some research has shown that the risk for anxiety or depression is higher for people who have experienced the death of their baby.

Diagnosing and treating anxiety and depression is very important but some things make it harder for families to get the supports and treatment they need. Sometimes feeling sad, negative, angry, or anxious is so difficult that people are not comfortable talking about it. It may be hard for people to believe that someone will understand how they feel. Often people feel ashamed that they are having these thoughts or feelings or are worried that people will think they are a bad or weak person. Some people are worried about being forced to take medication. Some people might not even notice how they are feeling until someone close to them shares their concern. Maybe you did try to talk to someone about it, but they didn't listen or respond in a way that was helpful, or you felt embarrassed. Maybe asking for help seems too hard.

Many of the thoughts and feelings associated with a baby's death or grief are the same as the thoughts and feelings associated with anxiety and depression, making it hard at times for care providers to determine what is happening or to tell them apart.

Talking to your family and care team about mental health is important. Signs of anxiety or depression may include:

- **Low mood or extreme sadness.**
- **Significant or lasting feelings of worthlessness or hopelessness.**
- **Feeling guilty, inadequate, anxious, or panicked.**

- **Drug or alcohol abuse or a big increase in use.**
- **Changes in how you function every day – not eating, bathing, getting out of bed.**
- **Problems with sleeping or eating.**
- **Difficulty concentrating.**
- **Thoughts of hurting yourself or others.**

If you have a personal or family history of mental illness, or if you are worried about your thoughts or feelings or want more support, let your care provider know. Book an appointment with your primary care provider (doctor, midwife, or nurse practitioner). At the appointment, tell them that you would like to talk about your mood, or take the opportunity to talk about your mood when asked, *“How are you feeling?”*

It is important to tell someone if you are feeling overwhelmed, finding it difficult to cope, or if you are having thoughts of harming yourself or others. Your care provider will work to understand what is happening and refer or connect you with supports for you and your family if necessary.

Some families also find it helpful to:

- **Reach out for support. Talk to a close friend or family member. Join a support group. Connect with an elder or a community or religious leader. Talk to a mental health professional.**
- **Connect with the local Public Health Department. There may be nurses or trained volunteers who can help you and tell you about supports in your community. They may be able to come to your house to visit you. These services are free.**
- **Talk to other parents who have experienced mental illness.**
- **Talk to a crisis support line (search ‘crisis support line Ontario’ or ‘crisis support line [your city]’) or crisis volunteer.**
- **Get support from a mental health organization. In Ontario, the Canadian Mental Health Association has a website with information on mental health and mental illness and links to support. The Mental Health Helpline (1-866-531-2600 or <https://www.connexontario.ca/>) has information about free mental health services in Ontario and links to mental health**

service providers and organizations. On their website, you can search for services that are close to you.

If you are experiencing intense thoughts and feelings that put you in danger, such as thoughts of wanting to hurt or kill yourself, you should go to your nearest emergency department or call for emergency help (dial 911). You may also contact a distress centre or crisis line (search 'crisis support line Ontario' or 'crisis support line [your city]').

Grief and your relationship

If you have a partner(s), you may find that you each experience grief differently. You may each have totally different needs and it may be hard to support one another. This is normal. Because no two people grieve the same way or at the same time, you may find that there is hurt, anger, or sadness within your relationship. This especially happens when one partner thinks the other is not grieving or when one partner thinks the other does not care about them or the loss.

Sometimes one partner may feel that they are expected to remain outwardly strong to support the other. This can lead to one person hiding feelings of loss and sadness from their partner who is also trying to cope. In some cases, one partner may be required to keep working or to care for other children or the home, and they may wish to avoid getting outwardly upset so that they can do their work and tasks.

Sometimes one partner may play a bigger role in telling the other family members (including children) what has happened and what will happen in the future. It is important to talk with your partner about how you will handle questions from children, family, and friends and to talk about how they are coping with this often difficult task, or have someone else check in with them if you are not able to.

Many partners say that sexual intimacy after a baby dies is challenging, especially if one person is ready and the other is not. Sometimes after giving birth, people feel ashamed of or disappointed in their body. Sometimes physical symptoms such as pain, bleeding, or lactation make it hard for a person to feel sexual. Sometimes the sadness or anger makes it hard for a person to connect with their partner in an intimate way.

It is important that partners not blame themselves or each other, and to remember that they are both grieving the same loss. Although it may be difficult, it is important to try to be respectful of each other and how each person is grieving. It is common to miscommunicate or misinterpret each other. Talking about your feelings and thoughts with each other can be helpful because you can try to figure out how each person feels, what they need, and whether or not you can help each other. Some families also find it helpful to talk with a trusted person such as a friend, family member, or professional. Asking for help or talking to someone else doesn't mean something is wrong with your relationship.

Children's grief

Many families with other children at home will have questions about what to do or say during this time. For more information on this topic, please see *Appendix one* at the end of this booklet.

Special challenges

Special challenges

After a baby dies, families may face unique challenges including:

Lack of recognition: Families, friends, and healthcare professionals may not acknowledge the loss or may undermine its impact. They may not understand how you are feeling, know how to help, or know what to say. This may be especially true if your baby died right after birth, or if not a lot of other people got to meet your baby, or even knew you were pregnant. People may have different experiences than you, or may not be able to imagine what you are going through because they haven't been through it. Even if they have been through something very similar, they may have different beliefs or experiences than you.

Families may feel deeply hurt or judged or that there's a 'time limit' imposed upon them for returning to 'life as usual'. People may wonder or even ask you when you will 'get over it'. Some people may not mention your baby's death at all, such as when you return to work, or not understand how it impacts how you feel about other events, such as another person's baby shower or children's birthday parties. People may ask you rude or invasive questions, or avoid you and your family all together.

Sometimes families will hear deeply hurtful things, such as:

- *“Now you have an angel in heaven” or “They’re in a better place.”*
- *“Once you get pregnant again, you will feel better.”*
- *“At least the baby didn’t suffer.”*
- *“What did you do wrong?” or “I told you something was wrong.”*
- *“I wouldn’t have made the same decision as you.” or “You chose this...”*
- *“Try to be grateful for the children you have.”*
- *“God is protecting you from something bad that would have happened.”*
- *“It’s God’s will.” or “Nature knows best.”*
- *“Why aren’t you going to her baby shower?” or “Why won’t you come to my child’s birthday party? You’re selfish.”*
- *“You really need to get on with your life.”*
- *“Why are you always so sad?”*

Complicated feelings: Families may feel cheated or betrayed. They may feel a real sense of self-doubt, that they should have known something was wrong or done something to prevent it. They may feel angry with their body if their baby was born premature. They may feel overwhelming guilt if the death was because of their own or the baby's medical condition and a very difficult decision had to be made to stop the pregnancy. They may feel anger towards themselves, their partner, a healthcare provider, or friends. They may also feel sad or numb or hopeless. Families may feel angry that they did everything 'right' and that this still happened or upset that other people have 'easy' pregnancies or healthy babies. It can be very difficult to let go of a "*Why me?*" feeling. This feeling is very common for families to have for a long time after the loss of their baby.

Social isolation: After a baby dies, many families say they feel alone and isolated. Sometimes, there are few, if any, shared memories and parents may feel they are grieving alone. This may be even harder for families who had to travel away from home for pregnancy care, to give birth, or for specialty care for their baby. Parents may feel anxiety about being asked (or not being asked) about their baby and avoid others or social events. They also may avoid being around other pregnancies, babies, and/or children.

You may also feel alone and isolated if friends, family members, or co-workers have hurt you by saying something upsetting, or not saying anything at all to acknowledge your loss. You may feel hurt if some people didn't attend a ceremony, call to check in, or offer support in other ways. If your family does not talk about death or sad things or cry openly, you may feel alone or misunderstood. Things like this can make people feel reluctant to talk or to spend time with others who used to be a bigger part of their lives.

Often, family and friends want to do the right thing but they may be unsure of how to help or what to say. They may think that they know how you feel or what you are thinking. If possible, let them know how you feel and what you need during this time. For example, if someone says, "*let me know if there's anything I can do*", it can be helpful to give them something specific to do, such as to make dinner, vacuum, take the other kids out, walk the dog, or drive you to an appointment. If they are asking, they likely want to help.

Still, sometimes people will say hurtful or unhelpful things. If this happens, you may want to try to help them understand how you are feeling and that they are making it harder. Doing this takes emotional energy, and you may not always (or ever) feel like using your energy for this, especially if the person is not close to you. If you think you want to use your energy to help someone understand, you may want to say:

- *“I know you are trying to help, but what I need is really different.”*
- *“I hear what you are saying, but I do not feel the same way as you.”*
- *“What you are saying is hurtful” or “What you are saying is not helpful.”*
- *“I need...”* (space, understanding, you to leave, to be alone, someone to stay with me, help with meals, help with laundry, someone to walk the dog, to go out and not talk about it, etc.)

Taking care of yourself

Taking care of yourself

Physical healing and follow-up

If your baby died around the time that you gave birth, you will still need to have support for your own physical healing. Many families say that this time is hard because there is a lot going on, the focus may be on your baby and your grief, and you may feel like you just want to get away from the hospital or skip medical appointments. For some families, their baby may have been transferred to another location, and their main focus is to be with them. Professionals who care for families during this time wanted you to know that there may be some things you can do to help, including:

- If you are in a medical facility, asking if your healthcare team can come to you for checks. For example this may mean your nurse comes to check on you in the NICU, so you do not have to leave your baby's room.
- If you leave the hospital early, asking if you can have the option for a check-up sooner than is usually offered, if you need it. Many times, people will see their primary care provider in about 6 weeks after hospital discharge, if everything else is well. You may want to talk about the need to have a check-in sooner, if you feel that you were not able to get all your questions answered or needs met because you left quickly. You may also be able to arrange this with your primary care provider (family doctor or nurse practitioner), even if they weren't caring for you in hospital.
- Asking if you can have flexible appointments, meaning you may call and cancel or book an appointment with little warning. Your healthcare team may work together to give you this option knowing that how you feel changes day to day and you may need to cancel or come in last minute.
- Asking if you can have an early or end of day appointment to try to avoid waiting in a busy waiting room with other pregnant people or babies. You may also want to ask if it's possible to be placed in a room right away so you don't have to sit in the waiting room, or to wait in another spot, and have someone call you when a room is free for you.
- Ask if there is midwife support in your community that could do the follow up in your home.

Milk production after loss

Depending on the timing of your baby's death, you may begin to produce milk shortly after giving birth, have already been producing milk to feed your baby, or stopped feeding your baby with milk before they died. Many people say that milk production, or having to stop milk production, is another sad reminder of their baby that died and can feel cruel, shocking, and distressing.

Many families describe feeling anger towards their body or the situation, or deep distress that their body is making food for a baby who is no longer there. If you were producing milk for your baby, you may miss the time you spent together feeding your baby, and may find it hard that you no longer have to spend time doing the rituals or preparation that you used to do. You may feel deep sadness that you never got to bond with your baby in this way, or for as long as you wanted. Some families feel pride when they produce milk. Many families feel a combination of things. If you feel or think any of these things, you are not alone.

After your baby has died, what you decide to do with your milk will depend on many things.

What to do: Stopping milk production

Many families will decide to stop their milk supply after their baby has died. The biggest influence on milk supply is how fully and how often the breasts/chest tissues are emptied. When stopping milk production, the goal is to allow the breasts/chest tissue to remain as full as possible while avoiding painful or severe engorgement (filling of the breast/chest tissue).

You may find it helps to:

- Gently hand-express your milk if your breasts/chest tissues become firm by gently massaging and squeezing with your hand to remove drops or teaspoons, or pump to remove a small amount of milk for comfort. Doing this simply for comfort will not increase milk production, and it will help you avoid blockages and infection (called 'mastitis'). Right after hand expressing/pumping, apply cold compresses (described below).
- Put a cold pack or a bag of frozen vegetables on for 15 minutes. Do this off and on every 2-3 hours. To avoid damage, it is important not to apply the frozen items directly to your skin; instead, wrap in a wet

tea towel or cloth first. Do not use heat as this may increase breast/chest tissue swelling and increase your chances of an infection.

- Take pain medication such as ibuprofen or acetaminophen as needed, if safe to do so depending on your medical background. Both of these medications may be bought over-the-counter. Talk to your healthcare team to see if these medications are right for you. If you take the medications, follow the instructions on the bottle or from your healthcare team.
- Ask your healthcare provider about a prescription medication that suppresses milk production.
- For comfort, wear a comfortable (not tight) fitting bra or top that does not have an underwire (metal). Bras or tops that are too tight may cause problems such as blocked milk ducts or mastitis (infection). Wear what you find most comfortable.

There is no exact timeline for how long your body will continue to make milk, but this time may range from a few days to a few weeks. If you have any concerns or think you may have an infection, please contact your primary care provider (doctor, midwife, or nurse practitioner). You may also wish to call a local ‘breastfeeding’ clinic or your local Public Health department; explain why you are calling and ask to speak with a public health nurse. Some hospitals will have clinics with lactation consultants, nurses, or other healthcare providers that will be able to help you.

What to do: Continuing milk production and donating your milk

Some parents may decide to keep their milk supply as a way to stay connected to their baby or role as a parent. While some parents may do this for a short time, others may choose to do so for longer.

Some people will wish to explore pumping their milk and donating it to a Human Milk Bank. Milk that is donated may be given to very small or very sick babies, for example a baby in a Neonatal Intensive Care Unit (NICU). In order to become a donor, there is a screening process which may involve an intake phone interview or questionnaire, blood tests, and a health history form for your primary care provider to complete. To begin this process, please speak to a lactation consultant or member of your healthcare team, or visit the Human Milk Banking Association of North America’s website at www.hmbana.org to find a Human Milk

Bank near you. In Ontario, there is one milk bank, based in Toronto. They accept donations from all around the province.

Some parents have also found other options meaningful, such as saving and storing frozen milk in the home or having a piece of jewelry or other type of keepsake made by companies that specialize in this type of service.

Emotional support ideas

Emotional support ideas

Families tell us that taking care of yourself may feel hard, or even wrong at this time. If you feel this way, you are not alone. When possible, be gentle and kind to yourself. In this section we will talk about different ideas for taking care of yourself; what works for one person may not work for another. Please take what is useful here and leave the rest behind.

It may be helpful for you to know:

- **It's ok to do something that you enjoy, or that brings you comfort.**
- **What you find helpful, or what you want to do to take care of yourself or to honour your baby may change over time.**
- **You may feel very vulnerable at times and may not feel like reaching out for support or taking care of yourself. For some people, they will feel most vulnerable when they are doing something that is not private, for example going out in public, getting counseling, talking about their feelings with someone else, or going to a group meeting.**
- **A lot of people find it helpful to get help early on, but not everyone feels this way. You may need to wait to find help until you are ready. Some people will never feel ready for something so awful that has happened. Knowing this may help you get help even if you do not 'feel ready'.**
- **If you have a partner, you may find that you have different needs or experiences at the start. As you find ways to take care of yourself and do what you need, it will be easier to share this experience together, even if you do not feel connected to each other now.**
- **Even though it feels hard, many people say that reaching out for support is worth it at least once. Even if you do try and find that it is too hard to talk with someone, you can take a break before trying again. You may be surprised with how helpful it is to talk about what you are thinking or feeling.**
- **People seek support for different needs. For some, it is the need for connection with another person who understands. For others, it is the need to let out, or to make sense of thoughts and feelings.**
- **Sometimes people think, "*No one is going to say anything to fix things, so why talk about it?*" Even if no one can 'fix' what happened, it can still be helpful to talk about it.**

- Some people are afraid that talking about what happened will be too painful, but not talking about it does not make the pain go away either. Pain can be shared and let out. Although the pain can lessen over time, the grief in some form will likely be with you forever.
- Some people find it helpful to be in a group and hear other people's stories, while other people find it overwhelming. Being in a group can help you to know that you're not alone, and that what you are thinking and feeling isn't strange or unusual. You may find the privacy of reading other people's experiences online to be more comfortable at first, or always.
- Some people find it helpful to talk to a professional, such as a counselor or therapist. Some people think that if you go to a therapist, that means there is something 'wrong' with you, or that you are a 'weak' person, but this is not true. Many people will see a professional during this time to help them make sense of what has happened.

Some ideas for taking care of yourself include:

- Surrounding yourself with people who are kind, loving, and able to support you and your family.
- Talking about your thoughts and feelings with your partner, family, friends, elder, religious leader, community leader, or a professional.
- Taking a break from regular activities or responsibilities, and accepting help from others when possible. For example, you may want help with making meals, child or pet care, and housework.
- Honouring your baby in a way that is meaningful to you. You might: donate to a local charity, do something you enjoy while thinking of your baby, attend a memorial event, make a memento box, write a poem or letter to or about your baby, write in a journal, have a ceremony for your baby, wear a special piece of jewelry to commemorate your baby, light a candle, or plant flowers or a tree.
- Connecting with peers: join a bereavement support group, read other people's stories, meet with a friend who will listen to you as you talk, or talk to families who have had similar experiences.
- Taking time off work, if possible. Your healthcare providers may be able to assist with documentation that you need. Social workers often are able to help families with paperwork.

- **Trying to eat, sleep, and do a physical activity that you enjoy or can manage. Some people will find doing something physical easier than talking about their feelings. For example, you may be able to grocery shop, clean out your closet, cook, or go for a walk, but dread having someone over to talk. Some people may find that talking about their feelings is all they want to do. Both of these are normal. Do what you can manage.**
- **Saying “no” to something you do not want to do.**
- **Anything that brings you comfort. Take care to not choose things that put your health or safety at risk. If this is a worry for you, seek professional help early.**

Grief is natural, and in some form will be with you for forever. You can help it be a little bit less painful over time by taking care of yourself in ways that are helpful for you. Whatever you decide to do, the most important thing is that you get support and help when you need it. You are not alone in this journey of grief and loss.

For an up-to-date list of helpful resources, or to get support, please visit PAIL Network’s website.

Appendix one

Children's grief

After a baby dies, many parents are concerned about their other children.

PAIL Network has a booklet about children's grief that discusses some common fears and questions families have in more detail. The booklet suggests ways to support children through their own grief, words to say, and age-appropriate activities. For more information, or to order a free booklet for your family, please go to pailnetwork.ca.

For more information, or to find
support for yourself, please go
to pailnetwork.ca or call
1-888-303-PAIL (7245)



Pregnancy and
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