

LOVING AND LOSING:

Loss of a multiple



Pregnancy and Infant Loss Network
PAILNETWORK.CA

 **Sunnybrook**
PREGNANCY AND
INFANT LOSS NETWORK

Loving and Losing:
Loss of a Multiple

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

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

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

eMail - pailnetwork@sunnybrook.ca

Website - pailnetwork.ca

Who you can call for help

Your Healthcare team

Phone:

Public Health or Community Nurse
Please contact the health department in your community.

Phone:

Your Spiritual Care Provider and/or Elder

Phone:

Mental Health Support Team

Phone:

Local Crisis Helpline

Phone:

About Us

We are a not for profit organization that is dedicated to providing peer support to families* who experience the loss of their pregnancy or death of their 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, 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 Network 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".

PAIL Network would like to thank the families who reviewed this booklet and who shared their experiences for the benefit of others.

PAIL Network would like to thank the professionals who read through the booklet and provided their thoughts and expertise.

PAIL Network would also like to thank the contributing authors who shared their thoughts and expertise in order to support bereaved families.

Our contributing authors are:

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Dedication

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

What you'll find here

Definitions	10
Introduction	17
What will I learn from this booklet?	19
What is a multiple pregnancy loss and what causes it?	22
Medical Information	23
When a baby dies early in a pregnancy (under 20 weeks gestational age)	26
When a baby dies later during pregnancy (after 20 weeks gestational age)	28
When a baby dies after birth	30
Questions to ask	32
Some questions you may want to ask the healthcare team	32
A note about emergencies	33
Professionals	
Some professionals you may meet during this time	36
Respect for parents and babies	37
Rights for parents	37
Rights for babies	39
Saying goodbye: Memory-making	40
Professionals who support families want you to know	40
Ideas for memory making: during pregnancy	41

Saying goodbye: Memory-making <i>continued</i>	
Ideas for memory making: after birth-----	42
Cultural and spiritual traditions-----	43
Parenting your living twin or multiple -----	44
When in the hospital -----	44
Grief and loss: a lifelong journey -----	46
The following may be experienced after a baby dies... -----	46
Does everybody feel this way? -----	48
You might also consider support from a... -----	48
Beyond worry and sadness: Anxiety and depression-----	49
Talking to your family and care team about mental health is important... -----	50
Grief and your relationship -----	52
Children's grief -----	53
Special challenges -----	54
After a baby in a multiple pregnancy dies, families may face unique challenges... -----	54
Sometimes families will hear deeply hurtful things -----	55
Social isolation-----	56
If you feel able to help someone understand, you may want to say...-----	57
Taking care of yourself -----	59
During pregnancy -----	59
Physical healing and follow-up-----	60
Professionals who care for families during this time... -----	61
Emotional support ideas-----	62
Some ideas for taking care of yourself...-----	64
Resources -----	66

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. This may also be referred to as “palliative care”.

Often, the focus of care is on making sure your baby is comfortable and making the most of your time together 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.

Embryo and fetus

These are the early developmental stages of a baby and the medical terms frequently used. The early cluster of cells that implants in the uterus and grows from a fertilized egg is known as the embryo. The embryo will continue to grow until it is called a fetus from about 11 weeks until birth. In this booklet, we will often use ‘baby’ to refer to an embryo, fetus, or pregnancy.

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”.

Fetal abnormality or anomaly

This term may be used by a healthcare professional to describe a structural or chromosomal issue with a baby. For example, an ultrasound may find that the baby has a structural problem with their heart or brain or kidneys. Or a blood test may find that the baby has an extra chromosome, such as in Down Syndrome (Trisomy 21) or Edwards Syndrome (Trisomy 18), or another genetic disorder. Sometimes these ‘abnormalities’ can be fatal, life-limiting, or life-changing.

You will likely have many questions for your healthcare team if you hear these words. This is normal.

Infant death

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

A special note about Infant Death

PAIL Network has a booklet called “Infant Death: When a Baby Dies in Their First Year of Life” that talks about care of a baby in the hospital or a hospice around the time of their death.

While we will not talk about this in detail in this booklet, you may want to also read through that booklet if you want more information about what to expect during this time.

To access other resources, please visit our website here:
<https://pailnetwork.sunnybrook.ca/resource-library>
or scan this code.



Life-limiting diagnosis

A healthcare professional may use this term to describe a problem with the baby (either structural or genetic) that means that the baby's life will likely be very brief. This may mean that if the baby is born alive, the baby would be expected to live for only a short time. Sometimes it is hard to predict what 'brief' will mean. It could mean minutes, hours, days, or weeks.

Multifetal pregnancy reduction (MFPR) or Selective reduction (SR)

Multifetal pregnancy reduction is a procedure used to lower the number of babies (fetuses) in a multiple pregnancy. You may also hear this described as a 'fetal reduction'. In a MFPR or SR, a person is pregnant with more than one baby, and they make a decision to lower the number of babies that they will continue the pregnancy with.

For example, a person pregnant with triplets may reduce the pregnancy to twins, or a person pregnant with twins may reduce the pregnancy to a single baby. This is most often done to lower the risk in a pregnancy with more than one baby, or if there is an issue with one of the babies (for example, a genetic disorder). The most common way a selective reduction happens is through a procedure where medication is used to stop the heartbeat of one baby, but not another.

This booklet will not cover loss due to selective reduction in detail. If you would like more information, **please check out PAIL Network's booklet titled "A Difficult Choice: A Booklet for Families Ending a Pregnancy"**.

Multiple pregnancy

A multiple pregnancy is a pregnancy where there is more than one baby in the same pregnancy, for example twins, triplets, or quadruplets.

Neonatal death

The death of a baby within the first 28 days of 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 disorder, 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.

Unfortunately, stigma can also be something that is felt internally—a belief that someone feels about themselves or their situation which can make the experience of pregnancy and infant loss even more isolating. Pregnancy and infant loss can carry a lot of stigma.

Stillbirth

In Canada, stillbirth is the birth of a baby 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 talk about the loss of a baby due to stillbirth.

PAIL Network's also has a booklet called "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.

A special note about Sudden Unexplained Infant Death

Although we will not cover the death of a baby from Sudden Unexplained Infant Death in detail in this booklet, families who have this type of loss may wish to view or **ask for a copy of PAIL Network's booklet, "Infant Death: When a Baby Dies in Their First Year of Life"**, where the topic is covered in more detail.

In that booklet, we talk more about special service for families at the time, such as the Family Liaison Service, Compassionate Viewing, as well as the Next of Kin Clinic through the Office of the Chief Coroner and the Ontario Forensic Pathology Service.

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 baby 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"**.

Twin-to-twin transfusion syndrome

Twin-to-twin transfusion syndrome is a rare complication that happens in pregnancies where babies share a placenta, and the blood vessels that supply them with oxygen and nutrients. In twin-to-twin transfusion syndrome, one baby receives more of the blood supply (recipient), while the other baby receives less (donor).

The baby that gets most of the blood supply may have complications because too much blood supply can cause problems with their heart having to work too hard. The baby that does not get enough blood supply can have issues growing or with their organs. Both are at risk of death from this complication, if it is not caught early enough or treated.

Vanishing twin syndrome

Vanishing twin syndrome is when a pregnancy that was originally detected by ultrasound to be twins changes to a pregnancy involving only one baby, because one of the babies (embryos) stops developing.

At an early ultrasound (6-7 weeks), a family may be told they are carrying twins, only to find at the next ultrasound there is only one heartbeat and one embryo/fetus. This term is usually used to describe the loss of a baby in the first trimester. There is no way to predict if this will happen and no way to stop it from happening.

Viability, and borderline viability (periviability)

'Viability' means a potential 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 (or babies) has died.

Bereaved parents and healthcare professionals created this booklet to guide families through what to expect when experiencing the death of one or more babies in a multiple pregnancy. 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 this time. Reading this booklet can answer some of the questions you may have. There are many different reasons why a baby dies within a multiple pregnancy. Although there are other reasons, this booklet covers losses that happen because of:

- Sudden early loss of a baby. This is when early in a pregnancy a multiple pregnancy is discovered, only for one or more of the babies to die. An example of this may be vanishing twin syndrome.
- Problems with the pregnancy or health problems that may or may not have been identified during a pregnancy. These may have started because of pregnancy or birth complications.

Examples of this may be a pregnancy complication such as a sudden stillbirth of one baby, twin-to-twin-transfusion syndrome where one of the babies dies, or a life-limiting genetic issue or problem with one of the babies. The death may happen before the baby is born, or after birth.

- Prematurity, where one or both babies are born too early and one dies because they are too little to survive, or because they have health problems that are related to being born premature.
- Other reasons, such as health problems with one of the babies (for example infection or injury) or the death of a baby to Sudden Unexplained Infant Death Syndrome (SUIDS)

Families may be given this booklet at different times, including during their pregnancy if they know a 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.



What will I learn from this booklet?

This booklet is intended as an overview of experiences that may occur around the time of the loss of your multiple pregnancy or death of your baby. We hope the information in this booklet will help you better understand the loss of a multiple pregnancy or baby 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.
- You may also find that in some instances of a loss in a multiple pregnancy, it seems like professionals and family and friends don't think the loss is a big deal because you still have a live baby or viable pregnancy. This may be especially true if your loss was early in the pregnancy, or under 20 weeks gestational age, so the baby that died is not registered at birth.

For many families, the loss of a baby early in the pregnancy won't be discussed, or documented, or acknowledged for very long past the loss and this can feel like the baby who has died is being forgotten. This can be especially difficult if the family is grieving the loss of a baby, or multiple pregnancy, and it is not recognized by their family and friends.

- A family may also hear hurtful words like, "You need to focus on your pregnancy/living baby" or "At least you still have a living baby". These words are not helpful and can make people feel alone and like their other baby doesn't matter to other people.

- 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 unique type of loss happen, or because after their baby died they did not know where to turn for support, especially if they are focusing on parenting a living baby at the same time.

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, "Maybe we shouldn't have taken the risk of this pregnancy", or "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 losses in a multiple pregnancy happen for complicated, sudden, or unknown reasons. At other times, multiple pregnancies end prematurely or have complicated scenarios, such as babies sharing a placenta. In some pregnancies, one baby may be 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.

- When a baby dies, families often hear terminology that they are not familiar with and can make them feel like this is something that no else has experienced. Many families want to find connection with other families who have a similar experience. If you feel this way, you can ask your health care provider to explain the terminology and request peer support from PAIL Network.
- You may 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 a loss in a multiple pregnancy or 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 a multiple pregnancy loss and what causes it?

Every year in Canada, there are thousands of families who are pregnant with a multiple pregnancy, and many who sadly experience the loss of one or more babies during the pregnancy or after birth.

There are different reasons why a baby may die during pregnancy or after birth. Multiple pregnancies may have risks or complications more often than pregnancies with a single baby, and because of this, a loss may happen. Sometimes the loss happens early, without warning or a clear reason. Sometimes a loss happens because of complications with sharing a placenta, or because a birth happens very early and a baby dies from being born premature. At other times, a genetic problem with a baby or a health problem after birth causes a loss.

While this booklet is meant for families who have a loss of one baby in a pregnancy while another baby lives, we want to acknowledge that sometimes a multiple pregnancy ends in the loss or death of all babies, and that those families need support as well.



Medical Information

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

A family may:

- Experience shock or excitement with the news of a multiple pregnancy, and work to 'get used' to the idea, only to have that dream or those plans changed with the loss or death of a baby
- 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 for twins or triplets can suddenly change from what they had previously expected and this can be devastating.
- Experience worry about the surviving baby and what is going to happen, especially if they have health issues from the pregnancy or being born early
- 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 or 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 multiple pregnancies that had no complications, and wonder why theirs did. They may always wonder if they made the best decisions for their pregnancy.
- May be separated from their baby(ies) right after birth, whether at the same hospital or at different hospitals. They may feel like they lost precious time to be together or to have their babies together.
- 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 may feel even more alone and isolated.
- Feel anger towards the healthcare system or healthcare professionals, especially if they feel that not enough was done to monitor their pregnancy or babies, 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 babies. Their belongings may be there, as well as shared memories or hopes and plans. Maybe they had two car seats or two cribs ready, and now won’t be able to use them.
- 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 ambulance or other twins or triplets.
- Find that people ask nosy or insensitive questions about what happened

- Experience a sense of loss surrounding your identity as the parent of a multiple, and feel that there are very little supports for families, and very few people who understand this type of loss.

Maybe some of the supports you had planned on using are no longer available to you if you are not the parent of more than one living baby. You may also have made friends with other multiples families, and find it too hard to keep those friendships.



When a baby dies early in a pregnancy (under 20 weeks gestational age)

Sometimes, a multiple pregnancy will end with the death of a baby early in the pregnancy, which is usually defined as before 20 weeks gestational age.

Special challenges

There are some things that make having a baby die early in a pregnancy very challenging.

A family may:

- Experience the loss of a multiple very early, so that for the rest of their pregnancy, few people even acknowledge that the pregnancy was ever a multiple pregnancy
- Feel sad that their baby that died does not have a birth certificate like their living baby
- Feel shock and guilt when a loss happens, when the initial news of a multiple pregnancy may have felt stressful and took some getting used to
- Feel sad that few tangible mementoes after birth can be created for the baby that died
- Feel worry for the rest of the pregnancy that something will happen to the other living baby/ies
- Feel sad to lose out on the special excitement that happens with a multiple pregnancy
- Never get the answers they need or want as to why the loss happened

In Canada, when a baby dies before 20 weeks gestational age, there is usually no official registration or recording of their death or birth.

Although the time of birth for a baby may be different from when they die, for example if a baby dies in a multiple pregnancy before 20 weeks but the other baby lives and is born closer to the end of the pregnancy, most professionals will not register or record the birth of the baby that dies when the death happened before 20 weeks.

For many families, this will be upsetting. If you feel this way, you are not alone.



When a baby dies later during pregnancy (after 20 weeks gestational age)

Sometimes, a family may experience the loss of one baby in a multiple pregnancy through stillbirth. This may be unexpected and sudden, or the loss may have been already known to the family and professionals caring for them.

Special challenges

There are some things that make having a baby die later (after 20 weeks) in pregnancy very challenging.

A family may:

- Wonder if there was anything different they or the healthcare team could have done differently
- Hear words or language that make them feel guilty. They may be asked why they didn't come in sooner to be checked, or why they didn't know something was wrong.
- Feel sad that few tangible mementoes after birth can be created for the baby that died if it has been a long time between their death and birth
- Feel worry for the rest of the pregnancy that something will happen to the other living baby/ies
- Not know how to share with other people that you are carrying a pregnancy with one baby who has died
- Feel sad to lose out on the special excitement that happens with a multiple pregnancy

- Find out that their baby has died and there is risk to their other baby, and have to make hard decisions about what to do next, such as to give birth early. 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' but still have their baby die
- 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
- Never get the answers they need or want as to why the loss happened



When a baby dies after birth

Sometimes a baby in a multiple pregnancy will die after birth. Some reasons for this happening are because they were born early (premature), from a problem during the pregnancy or birth (for example, bleeding), because they get sick after birth, or from Sudden Unexplained Infant Death Syndrome.

Special challenges

There are many things that make having a baby from a multiple pregnancy die after birth especially challenging.

A family may:

- Wonder if there was anything they or the healthcare team could have done differently
- Have to make hard or 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 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.
- 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' but still have their baby die
- Feel worry that something will happen to the other living baby/ies
- Feel sad to lose out on the special excitement that happens with raising multiples
- 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 or emergency are avoiding them or unavailable to meet to talk about what happened
- Have a baby that is sick and bring them to the hospital for care, only to hear the news that their baby will die. A family may also worry that an illness could spread to other family members, including other children in the home.
- 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 if they have lived there with their baby. All of their baby's belongings are there, and there are many shared memories.
- Have to answer questions from people who don't know what happened, or who want to know private details

Questions to ask

Professionals who care for families around this time want 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 may be helpful to have someone with you to listen when you have questions, or if someone can't be with you in person, to have them on the phone. Professionals may not have the answers to your questions, but they will tell you what they know, and help you to understand the information. Sometimes, the information changes over time.

Some questions you may want to ask the healthcare team include:

- What will my baby look like when they are born?
- What will the birth look like?
- Do you think my baby will be born alive? How long will they live for? What if they live for longer? Shorter?
- What options do we have for where our baby (babies) will be cared for? Will I be able to hold them?
- Is it safe for me to hold my living baby and my baby who isn't alive at the same time?
- What type of care will my baby get? What is possible and why? Where will the care happen?
- Will my baby feel any pain or suffer?
- Is there a limit to who is able to be with us in the hospital?

- What professionals will be around?
- What memory making activities can we do?
- What is going to happen next?
- What supports are available after we go home? Who do I call if I have a question later on?
- Should I book a follow-up appointment? When?

My notes

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 babies are born unexpectedly and one 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, a living baby, 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, and you may find these emotions last for a long time, or come and go. If you are feeling like you can't stop thinking about this trauma, for example you are reliving the traumatic moments in your mind or dreams, you may find professional counselling helpful.

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 PAIL Network’s booklet on Infant Death for more information).

- For families who have a baby die unexpectedly at home or from an injury or crime, 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, or to focus on your living baby. 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.

Professionals

You will likely meet many different professionals who are caring for you, your pregnancy, and your baby/babies. Some of these professionals will continue to provide care for you when your loss happens. You may also meet new professionals around the time of your baby's death, depending on what else is happening in your pregnancy and where you are receiving care. Depending on where you are getting pregnancy care or giving birth, and the circumstances around your baby's death, you may meet professionals in an office or at a hospital, or at home after loss happens.

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
- Child Life Specialists (to support living children in the family)
- 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

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. Depending on when your baby dies, there may or may not be a chance to see and hold and touch them. Talk with the professionals caring for you, as they will be able to help you understand what to expect and what is possible. Even if you can't make physical mementos, you can still honour your baby in other ways. We will talk about some other ideas further on in this booklet.

Rights 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 (for example, 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 see, touch, hold, and nurture their child with no limitation as to time or frequency.
- 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.

Rights for babies

- To be acknowledged by name
- 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

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. Your care team will be able to help you understand what to expect and what can be done. It may 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.

For some families, they may not be able to have a lot of physical mementos made, especially if their baby died really early in the pregnancy or if it has been a long time between when their baby died and when they were born. It can also feel very sad to not be able to make these memories with your baby. If you feel this way, you are not alone.

Professionals who support families want 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 (ultrasound pictures or reports, photos, handprints, etc.) can be helpful for people who are grieving.
- Sometimes, the decision to do this or not do this is based on a family's religious, cultural, or spiritual beliefs or values. It may help to talk to your healthcare team, religious, knowledge keepers or cultural leaders during this time. Some families may want to continue family traditions and others may not, or may start new traditions. Many families will do a combination of things.

- You may want to have photos of your babies together if this is possible
- 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 or a Child Life Specialist 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. If it's not possible at the hospital, a funeral home may be able to assist with this.
- 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 babies, and to make memories during this time. Many families will want to focus on special moments, such as picking a name, writing down special moments in a journal, and doing things they enjoy 'together' as a family. It is also understandable and okay to not enjoy your pregnancy or focus on these things. There is no right or wrong way to feel.

Ideas for memory making: during pregnancy

If you find out that one of your babies will pass away in utero or soon after birth, you might want to create some memories during pregnancy. Creating memories can help with the process of grieving.

Your care team might talk to you about different ways to make memories. Take into consideration what is important to your family, your cultural background, and your family traditions.

You might want to:

- Ask your care team to give you copies of ultrasound images

- Video record your ultrasound sessions
- Book a 3D ultrasound session that will capture the baby's images and video recording. Some centres offer a teddy bear with the recording of the baby's heartbeat. The cost of this service varies.
- Take pregnancy photos
- Take family photos or a family portrait, and think about other special pictures (for example grandparents placing their hands on the belly)
- Writing in a journal
- Buy, sew, or knit matching outfits for all the babies and keep one for yourself

Ideas for memory making: after birth

- Naming your baby
- Holding, snuggling, and kissing your baby
- Giving your baby a bath, changing a diaper, dressing your baby
- Having friends and family visit (consider using technology if not possible in person)
- Buying matching outfits for all the babies
- 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, blood pressure cuff, blanket etc.
- Taking photographs (separate and together with their twin or siblings) and videos
- Making hand and foot prints or molds
- Reading and singing to your baby
- Having a special ceremony

- Family photos (pick a picture or object that reminds you of your baby to include)
- Keeping a picture of the baby or ultrasound in the house
- Special events – party, cake, or balloons for the baby that died
- Donating to a local charity
- Attending a memorial event
- Writing a poem or letter to your baby, journal
- Having a special place to visit that reminds you of your baby
- Wearing a special piece of jewelry
- Naming a star after your baby
- Doing something you enjoy while thinking of your baby
- Honouring your baby in another way that is meaningful to you

Cultural and spiritual traditions

If possible, 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.

Some parents will grieve and acknowledge the loss after the surviving baby(ies) comes home from the hospital. You might want to have a private funeral service or a religious ceremony with friends and family after the hospital discharge. It might be difficult to organize any service or ceremony while the surviving baby is still in hospital. It can be difficult to even recognize the need to hold such a service. Some families hold memorial services months or even years after the death.

Parenting your living twin or multiple

When in the hospital:

Spending time in the hospital (often in the Neonatal Intensive Care Unit) after a loss of a multiple may be hard. The hospital card might identify your surviving baby(ies) as twin or triplet A/B/C etc , and it can be a constant reminder that there is a baby who is gone. You might also come across a new staff member who is not aware that you have lost the sibling and ask about the baby.

Some hospitals will add a purple butterfly sticker or other special image to the chart or door, which is a symbol of a lost baby. You might also choose to write something on the white board of your baby's room or somewhere on your baby's bed space indicating that he/ she is a surviving multiple.

Professionals will come and check on you, often including a Social Worker. The care team will talk to you about the services available to you. Consider accessing all the support available, and know that if you decline a service when it is offered to you, you can always ask about it later on if you change your mind.

Some parents might feel guilt for spending time with the surviving baby(ies) and pumping or breastfeeding. Some parents have a hard time bonding with the surviving baby(ies) for fear of losing this baby as well. If the babies were born very preterm, the baby will go through procedures and might develop infections or problems that create more anxiety and fear. Parents say that the NICU journey is 'one step forward, 2 steps back' and that's hard for any parent, but especially for the grieving parent who has just experienced a loss.

The NICU can be a challenging environment, and many parents will choose to focus all their energy on the surviving baby(ies). Trying to bond, getting involved in the baby's care, holding the baby, and providing breastmilk, can keep you occupied and focusing on the present moment.

It's also important to celebrate your surviving baby's milestones. Babies in the NICU go through a lot, and acknowledging your baby's first bath, first hold, first breastfeeding, first time being off oxygen, first outfit they wear, etc. will be moments for you to cherish in the future.

It's very hard to cope with both a loss and a baby in the NICU. Take care of yourself and be kind to yourself. Give yourself permission to celebrate your surviving multiple(s) and how far they have come, and be gentle with yourself as you grieve.



Grief and loss: a lifelong journey

When a baby dies, families grieve the loss of their baby and the future they imagined. When a twin or multiple dies, a family grieves the loss of their baby while at the same time caring for a new baby. Other people may find it hard to understand how you are feeling, because this is a unique situation that most people will never have to face.

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 more 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 your due date, birthday, or anniversaries, or seeing another pregnant person or a family with living twins or multiples. 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
- Feelings of fear or anxiety for ultrasounds or medical appointments

- Feelings of fear or anxiety about giving birth, if one of your babies died during pregnancy
- 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' or 'balance' in the world
- Asking yourself, "Why did this happen?" or "What could I have done differently?"
- Feelings of fear that something bad will happen to your living baby or babies

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 your baby, when you hear about or see other living multiple babies, or when someone says something hurtful to you. 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 or there was nothing else that could have been done. Some people are angry that other people have healthy babies or pregnancies or feel very sad when they know that their living baby or babies will not have their sibling grow up with them. 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 support 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
- 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 the death of a baby. **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.

You may also be trying to focus on caring for your living baby, or staying well in your pregnancy, and feel that you can't stop for extra help because you don't have time or energy.

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. If you notice that the feelings of intense grief are interfering with your everyday functioning, this may be a signal that you could benefit from additional support.

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. If your living baby or babies are in the hospital, talk to a professional there. If you are at home, book an appointment with your primary care provider (doctor, midwife, or nurse practitioner) or ask someone to help you make an appointment. 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 or your living baby(ies), 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 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 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. Other times, one partner may feel so worried about the other person that they aren't able to connect with their own feelings and emotions.

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. One partner may feel that focusing on the living baby is most important, and think that they shouldn't focus on sadness or grief or the baby that died.

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. During a pregnancy, you may be worried something else will go wrong. 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. Caring for a living baby as well may mean one partner feels tired and busy.

It is never helpful for partners to blame themselves or each other, and to. Although it may be difficult, remember that you are both grieving the same loss and caring for a new baby and 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, especially if they knew about the babies or if they see their parents grieving. PAIL Network has a booklet about children's grief that talks about 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 booklet at no cost, please go to pailnetwork.ca.**

Special challenges

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

Caring for a living baby while grieving a loss: When a baby in a multiple pregnancy dies, families must grieve that loss while at the same time continuing on with the pregnancy or caring for a living baby. How do you tell people what happened? What do you do with all of the baby items that you bought? Do you set up a room or area for your living baby, or make changes to it?

Some families who have been through this suggest:

- Sending out birth/death announcements by card or email to let people know what happened. You may want to do this yourself or have a friend or family member help.
- Keeping replies to your emails/cards for a time when you wish to read them. One mom who lost a twin before birth said she read the replies to the email announcement many years later.
- Do what feels right with setting up or changing the room or baby's area in your home: wait until you are ready.
- Do what feels right with the extras of things you bought or were gifted: return to the store, donate them, keep them.

Lack of recognition: Families, friends, and healthcare professionals may not acknowledge the loss or may undermine its impact, especially if you have a living baby. 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 early in the pregnancy or if few people knew you were pregnant with multiples. 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', especially with a living baby or babies to care for. People may wonder or even ask you when you will 'get over it' or tell you to 'focus on your living baby' or to 'stop being sad' so you can care for your living baby. Some people may not mention your baby's death at all, or not understand how it impacts how you feel about other events, such as ultrasounds or medical appointments. 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." or "They're in a better place."
- "At least you have a healthy baby" or "Your baby needs you to not be so sad all the time."
- "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."
- "Allah is protecting you from something bad that would have happened."
- "It's God's will." or "Nature knows best."
- "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 babies were born premature or if their placenta ‘stopped working’. They may feel overwhelming guilt if they had fertility treatments or question if they made the right medical decisions when they found out about their multiple 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. When a baby in a multiple pregnancy dies, a person may feel alone in their grief if people only focus on the living baby and do not provide spaces to talk about the baby that died. 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 pregnancy or baby. Parents may feel anxiety about being asked (or not being asked) about their pregnancy or birth or baby and avoid others or social events. They also may avoid being around other pregnancies, babies, and/or children, especially if they are twins or triplets.

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 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.

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 feel able 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.)

Fear: When a baby dies, a family knows what it feels like to have the worst thing happen to them, and this disrupts their sense of safety. They know that bad things can happen to good people and that sometimes you cannot control what happens. When one baby dies and another is alive, a family may have extra fear that the worst is going to happen to their other baby or children as well. If a baby dies in pregnancy, the family may feel fear for the rest of the pregnancy. If a baby dies after birth, the family may be worried that their other baby will die as well, even if people and professionals tell you that it is not likely to happen. Some families say that having their baby die changes how they parent and how they act, because they are scared that their other baby or children will be taken from them too. People in your life may not understand your fear, and may tell you that you are overreacting or too worried about things. If you feel this way, you are not alone.

Holidays and anniversaries: Some days will be harder than others and triggering. Many families say they find the first birthday particularly difficult. On the months and weeks leading to the first birthday, you might find yourself playing back all the events that happened the year before. Sometimes, every detail will pop up in your head, maybe ‘what ifs’, the due date, the birth date, the death date.

You might look at all the memories you created during pregnancy or the hospital stay. It might be very hard to be able to plan a birthday party or celebration for your surviving multiple(s). Not everyone will feel comfortable asking or talking about the baby you lost. Families have shared some ideas to cope with the first birthday and what to do to celebrate the surviving baby(ies):

- Plan a small gathering with close family members and friends
- Have something displayed to remember the baby
- Do something special, like release balloons, eat cake, visit a special place

It’s also ok if you don’t feel like having people around or having a party. Do what feels right for you and your family. Remember – this may change over time. You may also want to ask someone to help you with planning if you do not feel like doing it yourself, but you still want to do something to remember and celebrate your surviving baby.



Taking care of yourself

During pregnancy

If your baby dies during pregnancy, you may find that you will feel worried for the rest of your pregnancy. If your baby dies early in the pregnancy (before 20 weeks), you will likely hear professionals talking about their plan to monitor you and the other baby or babies closely. They may not be able to give you clear answers on what happened, and clear answers on when you will give birth. Not having this information and waiting after every ultrasound or appointment to find out results is very hard.

If your baby dies later in pregnancy (after 24 weeks), you may find that professionals want to talk about when and how you will give birth. They may not have all the answers for you and you may find that you are given information that makes it hard to know what the best choice is. Should you wait to give birth with close monitoring of your pregnancy? Should you give birth soon, even if your other baby is born early (premature)? What is safest?

Each decision may be difficult, especially if your care team tells you that there are many other unknowns. You may have to stay in the hospital or be transferred away from your home community for specialty care.

If your surviving baby(ies) have to spend time in the NICU, the care team can help you navigate the days and weeks after your baby's death. If the baby that died was in the NICU, consider whether or not you would like your surviving baby(ies) moved to a different area away from where the death occurred. Some families find comfort in remaining close to the space that their baby was cared for, while others find it difficult to see the space and watch other babies be cared for there.

While in the NICU many parents may be reluctant to leave the

surviving baby out of fear that something bad may happen while they are away. If you are feeling this way, you are not alone. Small steps such as going for a short walk around the hospital grounds may be a good way to start if you are not comfortable going home. Over time, you may feel more confident leaving for longer periods of time.

Focusing on the surviving baby(ies) can be overwhelming for some parents, which may mean you forget to take care of yourselves. Making sure you eat regularly, drink plenty of fluids, and get enough sleep is important for both your physical and mental health. Many parents find focusing on something they can enjoy while with their baby can help pass the time in the NICU. This may be something like watching movies or tv shows on a tablet with headphones, reading (silently or out loud to their baby), journaling, or doing a craft.

When possible, share your thoughts and feelings with your care team. Your care team should listen to you, explain what they know and do not know, and give you information about how they will monitor you and your baby and what they are watching for. Ask your questions, even if you have asked them before. You can ask to speak to a certain professional again if you have follow-up questions or want to hear the information again. You may want to ask to be connected to additional supports, such as a Community or Spiritual Leader, Social Worker, or Mental Health Professional.

Physical healing and follow-up

If your baby dies during pregnancy or shortly after 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 living 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.

You may have to travel a lot and find that you do not have time for much else.

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 (midwife, 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 a family member to remind you to book an appointment around 6 weeks after you gave birth
- 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

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, and know that your emotional needs may change over time.

It may be helpful for you to know:

- It's ok to do something that you enjoy, or that brings you comfort
- It's ok to enjoy your pregnancy or to feel joy and happiness. It's ok to feel joy and happiness with your living baby. This does not mean you don't love your baby that died, or that you are not honouring them.
- 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 help. Knowing this may help you accept support 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 a natural response to loss, and in some ways it 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 (pailnetwork.ca).



Resources

Helping others understand your grief

At PAIL Network, we have learned from families that trying to explain what they need or what would be helpful can feel like an additional burden for them to carry.

PAIL Network has shareable and printable resources that may help friends, family members, and co-workers better support families around the time that their baby dies.

To view these resources, please go to pailnetwork.ca (under resource library, 'Helping Others Understand Your Grief') or use your phone camera to scan the QR codes below.



FAMILIES



FRIENDS



COWORKERS



EMPLOYERS

ADDITIONAL RESOURCES FROM PAIL NETWORK

- [Supporting Siblings After Pregnancy or Infant Loss](#)
- [Silent Birth: When a Baby Dies After 20 Weeks of Pregnancy \(Stillbirth\)](#)
- [Miscarriage: Pregnancy Loss Before 20 Weeks](#)
- [Pregnancy After Loss](#)
- [Infant Death](#)
- [A Difficult Choice \(Ending a Pregnancy\)](#)
- [Milk Production After Loss](#)
- [Support for Grandparents](#)
- [Helping Others Understand Your Grief](#)





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