

Silent Birth: When a Baby Dies After 20 Weeks of Pregnancy (Stillbirth)



Pregnancy and
Infant Loss Network

 **Sunnybrook**
PREGNANCY AND
INFANT LOSS NETWORK

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

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

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

E-mail: painnetwork@sunnybrook.ca

Website: painnetwork.ca

Your pregnancy care team (doctor, midwife, nurse)

Phone:

Public Health or Community Health Centre

Please contact the health department in your community.

Phone:

Your spiritual care provider, clergy, community leaders, or elder

Phone:

Mental Health Support Team

Phone:

Local Crisis Helpline

Phone:

*Silent Birth:
When a Baby Dies After
20 Weeks of Pregnancy
(Stillbirth)*

About Us

We are an organization of peers supporting families who have suffered pregnancy and infant loss. We achieve this through education and peer, online, and telephone support.

PAIL Network is able to offer its services to bereaved families and healthcare professionals 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 us at pailnetwork.ca.

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 professional health and medical care or advice.

Throughout this booklet, gendered language is sometimes used in explanations (i.e. vaginal bleeding) 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, and inclusive of their gender identity or expression.

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 supported the writing of this booklet to ensure it was reflective of their experiences.

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.

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Introduction

What to Expect From This Guide

We are deeply sorry that you have experienced the death of your baby. Bereaved parents and healthcare professionals created this booklet to guide you through what to expect when experiencing a stillbirth, which is defined in Canada as 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. The baby may have died during pregnancy (called intrauterine death), labour, or the birthing process. 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 following your loss. Reading this booklet can answer some of the questions you may have at this time. Some people will be given this booklet while they are waiting to have their baby, while others will be given it after their baby has died and are going home from giving birth, or sometimes much later. 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 physical and emotional experiences that may occur after the death of your baby. We hope the information in this booklet will help you better understand stillbirth 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 a stillbirth, including shock, sadness, shame, guilt, anger, and self-blame. If you feel these things, you are not alone.
- After a stillbirth, many families wonder if there is something that they did to cause the stillbirth or something they did to cause the baby to be sick. Families may think “if only I did...” or “if only I didn’t do...” or “if only I had gotten checked sooner”. If you feel or think these things, you are not alone.
- Most stillbirths happen for complex, complicated, sudden, or unknown reasons. At other times, stillbirths are because of a difficult choice that families must make. No matter the reason, it never helps to blame yourself.
- You will have special needs during this time and deserve a care team that is kind, helpful, and supportive. There may be many care options offered to you and your family and you should choose what is best for you. We will talk about these options further below.
- In Canada, care providers and families have certain legal requirements when a baby is stillborn. We will talk more about these requirements 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 stillbirth 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 more significant and times where your grief feels very manageable. This is normal.

Words, Meanings, & Special Terms

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. The baby may have died during pregnancy (called intrauterine death), labour, or the birthing process.

Intra-Uterine Death, or IUD

When the baby has died in the uterus (womb) after you have reached your 20th week of pregnancy.

Neonatal Death

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

Infant Death

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

Perinatal Death

Includes stillbirths and deaths in the first week of life. The perinatal period starts at 22 completed weeks (154 days) of gestation and ends at seven completed days after birth.

Perinatal Hospice

Perinatal hospice and palliative care is a model of support that families may choose when they know their baby may die before or shortly after birth. This specialized support is provided from the time of diagnosis through the baby's birth and death.

Miscarriage

The early delivery of a baby (embryo or fetus) or loss of a pregnancy prior to 20 weeks gestation.

Embryo and Fetus

These are the early developmental stages of a baby and the medical terms frequently used. The early cluster of cells that grows from a fertilized egg is known as the embryo. The embryo will continue to grow until it is called a fetus from 12 weeks until birth. In this booklet, we will use 'baby' to refer to both an embryo and a fetus.

Uterus

Commonly known as the womb, the uterus is a reproductive organ in the pelvic region. In most cases, this is where a pregnancy develops and a baby grows.

Cervix

Narrow, neck-like tissue that forms the lower part of the uterus. The cervix connects the vagina (birth canal) to the uterus, and opens to allow passage between the two.

Dilation and Curettage (D&C)

A short surgical procedure where the cervix is opened (dilated) and tissues from the pregnancy (i.e. placenta) are removed from the uterus. This is done by removing (scraping or suctioning) the uterine lining. You may be 'put to sleep' (have general anaesthetic) for this procedure, or have another form of pain relief (i.e. spinal anaesthesia). The D&C is done in a hospital operating room.

Induction of Labour

The process of helping a person to start labour. This may be done by giving medications to help the uterus tighten or contract (contractions) or to make the cervix soft and open. It may also be done with procedures, such as using the balloon of a catheter to help the cervix open.

Foley Catheter

A thin, flexible, sterile tube that is often placed in the bladder to drain urine. Sometimes foley catheters are used to induce labour. They are placed through the cervix and a small balloon at the end is inflated with liquid (sterile water or saline). This balloon places pressure on the cervix, causing it to slowly open. Sometimes, people will have a foley catheter and medication together to induce labour.

Epidural (for labour pain)

Drugs used to reduce or remove pain are passed through a tiny, flexible tube into the small of your back. An epidural numbs only certain areas (for example, the ones that hurt during labour), so not all of your body is affected. Epidurals are started by specialty doctors (called anesthesiologists) and monitored by your healthcare team.

What is a Stillbirth and
What Causes It?

What is a Stillbirth and What Causes It?

Although there are different definitions of stillbirth around the world, in Canada, stillbirth is defined as 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. The baby may have died during pregnancy (called intrauterine death), labour, or the birthing process (just before they are born).

The World Health Organization reports that worldwide, there are approximately 2.6 million stillbirths each year. Many experts suggest the number is even higher. Most of these deaths (98%) occur in developing countries. In Canada, approximately 9 babies are stillborn every day. That's one baby, one family, every 2.5 hours. Stillbirths are almost 10 times more common than Sudden Unexplained Infant Death (SUID or SIDS).

Stillbirths are a very sad and shocking end to some pregnancies. You may wonder why it happened or blame yourself. While we know there are some risk factors that place people at a higher risk of experiencing a stillbirth, a stillbirth can happen to anyone and can happen even in a pregnancy that has been going well or where there are no other risk factors. In fact, the majority of stillbirths happen in otherwise healthy, low-risk pregnancies.

In many cases, no one knows what causes the stillbirth. Sometimes, a cause is found.

A stillbirth may be caused by:

- A problem with the baby's health, such as slow growth or chromosome or genetic problems with the baby
- A problem with the pregnant person's health, such as high blood pressure, diabetes, or a blood-clotting problem
- A problem with the placenta, such as the placenta being too small or tearing away from the uterus too soon
- An infection in the pregnancy
- A problem with the umbilical cord where the oxygen is cut off to the baby
- A problem with the uterus or cervix
- Early labour (natural or induced) or complications during labour or when giving birth

Medical Information

A stillbirth can happen for many different reasons and at different times, such as during the pregnancy (after 20 weeks gestation), during labour, or just before birth. Some families will find out that their baby has died during a routine appointment or ultrasound, while others will find out after going to the hospital or to a medical appointment for another reason, such as bleeding or labour.

Some families will have to make a heartbreaking choice about their baby. Some families will find out their baby has died just before they gave birth because of an emergency or problem during the labour or birth.

No matter the timing, finding out your baby has died or will die is a terrible, shocking, and tragic event. What happens next depends on the circumstances of your baby's death and your pregnancy, where you live, and what choices you make with your family and healthcare team.

Making Decisions

Unless their baby dies just before birth, many families say that the time right after they learn their baby has died is especially difficult because they are asked to start to make decisions about how and when their baby will be born. If you are alone, you may find it helpful to have a care provider call your partner(s) or your support people so they can be with you, listen to the information being provided, and ask questions.

Although it will be difficult, it is important to remember that you can ask as many questions as you would like and ask for information to be repeated to you and your family. Some families find it helpful to have information written down for them, so they will have a chance to review the information before they make decisions about their baby.

What do I do next? Where Do I Go?

If your baby dies before you are in the hospital, you will likely have a discussion with your care team about when and where you will give birth. For most families, the hospital will be where they will go. Many families say that they are scared or anxious and that being admitted to the hospital for medical care can be quite scary as you face many unknowns. If you feel this way, you are not alone.

Where you are admitted and the staff that will care for you depends on the community in which you live. For example, it may be emergency room staff, maternity staff, surgical floor staff, or a combination of many different people and care teams. Sometimes, families will have to wait for a little while to be seen or have to return to wait at home or in the community until there is an opening at the hospital for them on the floor where they will give birth. Because the hospital and staff will have to wait until it is time to admit you, which may depend on having the right staff or physical space/room, this can take several days or even longer.

Waiting at home or in a hotel while knowing your baby has died may be especially distressing for families, who feel that they have been forgotten or that they and their baby are not important to the healthcare team. Many families simply want to hurry up the process. During this time, many families are upset, scared, angry, and confused. If you are feeling this way, you are not alone.

You may find it helpful to:

- Talk to a professional, such as a social worker, nurse, or doctor about taking time off work. Sometimes they can assist you with documentation that you need for your workplace (or your partner's workplace).
- Ask for a contact person at the hospital or for someone from the hospital to give you updates about the timing of your admission
- Ask a close friend or family member to stay with you or check in with you regularly
- Ask for help with making meals, pet or child care, or giving updates to friends and family members

Admission to the Hospital

Although every hospital will have its own policies and procedures, once admitted to the hospital you will be cared for by a variety of healthcare professionals. They will be able to explain the process and answer any questions you may have, while also providing the support and resources needed to help you and your family cope during this time. You may find it helpful to have a family member or friend with you at this time, to help to listen to what is being said and to ask questions for you. Remember you can ask for information and explanations more than once.

Once admitted to hospital you may request:

- To be admitted to a private room or area
- To have a symbol of loss — such as a butterfly — placed on the outside of your door. This is so that all staff entering your room know about your stillbirth.
- To be introduced to your primary healthcare team (doctor, midwife, nurse, anesthetist, social worker, spiritual care provider, etc.) and to have time to ask questions
- To be given the opportunity to identify support person(s) or comfort measures (including a birth plan) to help you cope during the time leading up to, during, and after delivery
- To discuss how you wish to give birth to your baby and the pros and cons of vaginal or caesarean birth
- To have the process of labour, induction of labour, and what to expect after delivery explained to you
- To be given options for pain management
- To discuss the plan after delivery, including follow-up and supports in your home community

Perinatal Hospice

Some families will know that their baby may not survive the birthing process, or if they do, they will only live for a short time. When this is known in advance, sometimes these families will want and be able to choose perinatal hospice. Perinatal hospice, and neonatal or infant death, is not covered in this booklet. For more information, please go to pailnetwork.ca.

Asking for a C-Section

Many families experiencing a loss cannot imagine going through the pain of a full labour and giving birth to their baby and will request a caesarean section (c-section) right away. Sometimes this is because of shock, fear, anger, or distress. Your healthcare team will discuss this with you, including the current and future risks and concerns of a surgery with you. Most care providers will encourage avoiding a major surgery if possible.

How you have your baby is a decision that you and your healthcare team will make together. It may help you to know that if you immediately feel like you want a c-section, you are not alone in feeling this way.

Induction of Labour

If your baby has died before labour has started, labour may need to be induced to enable your body to deliver the baby and placenta. This means that you may be given medication to help your body go into labour or have other help. Before you are given medication or other procedures, your healthcare team will speak to you about the process, such as helping to make your cervix ready for labour. Your healthcare team will be able to talk with you about the best options for your specific circumstances and explain the process to you in more detail.

Many families say that they are in shock when they first learn their baby has died, and have a hard time remembering exactly what was said to them right after. Remember you can ask as many questions as you would like, and ask for details or explanations more than once.

It may take several days, or longer, for your healthcare provider to schedule the induction of labour. You may also choose to discuss the possibility and safety of waiting for labour to happen naturally. While the wait may be very difficult emotionally, it can also allow time for you to:

- Think about what will be important to you during and after the birth, including how you may want to involve other family members (children, grandparents, etc.)
- Arrange for family members or loved ones to be with you
- Arrange for a photographer to be brought in to create special memories
- Consider what special services or other ceremonies you would like performed
- Ask questions

The Process - Starting Labour

Before beginning an induction, your healthcare provider will check your cervix for dilation (opening). They will do this by using their fingers to feel your cervix, by doing a vaginal exam. If your cervix has not yet started to dilate, you will require medication or medical techniques to help this happen. There are a number of ways this can be done depending on the facility you are in.

Medical management may include using medications. If you are given medication, it may be placed in your vagina (close to the cervix) or given through an intravenous (IV) line, or both. You may also hear from your care team that you need other help to go into labour. For example, your care team may talk to you about helping your body to be ready for labour by using a foley catheter (balloon) to open your cervix.

The goal of these interventions is to cause softening of your cervix and cramping (from your uterus) so that your cervix starts to open and you start to labour (have regular contractions). Regular contractions that help your cervix to open is often called 'active labour'. If the methods used above do not bring you to 'active labour', your care team will discuss next steps with you. Some people may also be offered to have their 'water broken' (membranes ruptured artificially). This is done using a special tool to make a small hole in the sac of fluid around the baby. Often this helps to make contractions stronger and closer together.

While the medications we discussed above often work very well, in some cases labour doesn't happen or the medications don't give strong and regular enough contractions to open your cervix and help the baby move down into the pelvis. If these approaches don't result in delivery of your baby and the placenta you will be reassessed by the healthcare team taking care of you. At some point, they may discuss a cesarean section (c-section) with you.

Throughout labour, your healthcare team will watch your blood pressure, pulse, and breathing (vital signs) and your labour progress will be closely monitored (cervix opening, contractions, bleeding). During this time you may have your support person or people with you. Many families say that this process is a scary, sad, and tiring time. Ask your healthcare team any questions you have. Some families find it helpful to talk with their healthcare team about what to expect throughout the process and at the time of delivery. Other families do not want to talk about the process or delivery and rely on the healthcare team to tell them information when it's important for them to know. There is no right or wrong way to approach this time, so please do whatever feels best for you and your family.

The Process - Pain Management

You will most likely be offered some sort of pain management when you are in labour. The type of pain management available to you will depend on where you live and what hospital you are receiving care from. Your healthcare team will be able to discuss this with you in more detail. They will also be able to talk to you about pain management techniques that don't involve medication, such as special positions, massage, emotional support, movement, and water.

If available, it is very common to be offered or receive an epidural. An epidural lasts as long as needed and often provides good pain relief. If you are interested in other options, you could receive pain medication (narcotics) through your IV or you could be offered a PCA (patient controlled analgesia) pump. This pump allows you to be in charge or your own pain relief. It works by having you push a button when you feel you need pain relief. The pump can stay with you for as long as it is needed. While you are using the pump, your healthcare team will watch you closely and talk to you about how you are coping with the pain. Depending on where you live, you may also be offered laughing gas (nitrous oxide) to help with the pain.

The Process - Giving Birth

Your healthcare team will monitor you throughout your labour and help to assess when it is time for you to begin pushing. This usually happens when your cervix is all the way open, although sometimes birth can happen before that, depending on the size of your baby. Sometimes the process of labour and pushing takes a long time, and other times it is very short or sudden. After your baby is born, you will also have to pass or birth the placenta. Sometimes the placenta comes out very quickly, while other times it comes out more slowly. Sometimes, people need extra help for their placenta to come out (medication, removal with a healthcare provider's hand, or surgery).

Caesarean Section

Depending on your own unique medical history and the situation of your birth, you may need to have a caesarean section. Some families will have this because of the medical needs of the pregnant person, for example if they've already had a caesarean section before or it's not safe for them to labour because of bleeding or other issues.

Other times it will be because of a choice a family makes in consultation with their healthcare team. Sometimes families will have a caesarean section because of an emergency surrounding the birth, which we will discuss more below.

It is important to remember that regardless of how you give birth, you will need care and support from your healthcare team. Your healthcare team will be able to answer any questions you have, support you in spending time with your baby, and provide the necessary physical and medical care needed.

A Note About Emergencies

Sometimes there are emergencies surrounding the death of a baby to stillbirth. This may be because a family comes into the hospital with a pregnancy concern and there is a rush to deliver the baby, but the baby dies before birth. Sometimes there is a concern or emergency issue while a person is in labour or when pushing to deliver the baby

and then there is a big rush to deliver the baby, sometimes by surgery, but the baby does not survive. At other times, the health of the pregnant person is at risk, for example with high blood pressure or severe bleeding, and the healthcare team must focus on keeping them healthy and saving their life.

Sometimes, doing this means knowing that the baby may die. Sometimes, the pregnant person is very ill and taken to a specialty unit or the closest Intensive Care Unit 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. Coping with an emergency situation or other traumatic events on top of the death of a baby can be extremely difficult. You may feel shock, anger, sadness, numbness, or extreme distress. It is normal to feel these things. Your healthcare team will be able to help you and your family during this time.

It may be helpful to remember:

- Often there is no rush to make big decisions, such as funeral arrangements. You can take your time to make some of these plans until everyone is together.
- You will likely need physical care and monitoring, as well as emotional support. Your care team will help you with pain management and monitor you for safety.
- Often there is no rush to make decisions about seeing and holding your baby and making special keepsakes. The healthcare team will be able to 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 have questions. Sometimes families are able to get their questions answered before they go home, while others will ask for an appointment after to talk about what happened. You can ask your healthcare team to have this meeting with you, if it's not offered.
- 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. After, you may find that you are really struggling with everything that happened and wondering what to do. You may have nightmares or constantly wonder 'if only'. There is help during this time, but you or a loved one may need to reach out and ask for it. For many families, this can be extremely difficult.

Self Care Check-In
How are you doing?

Special
Rights

Special Rights

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

Rights of the 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.

Rights of the Baby

- 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 receive mementos of their baby (e.g. footprints, picture, certificate of life)
- 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 Hello
and Goodbye:
Memory Making

Seeing and Holding Your Baby

Following the birth of your baby, you will be given the opportunity to spend time with them if you choose to do so. They are your baby, and only you should make this decision for yourself. Families make different choices and it is common for parents to change their mind about what they want to do. It may help to know that many families are glad that they spent time with their baby, even when they initially thought that they did not want to do so. We know that few parents ever regret the decision to see and hold their baby. What you decide to do is sometimes a complex decision and ultimately up to you. Your care team will support you and talk through your thoughts and feelings with you.

It is ok to ask your care team to guide you through this time and to suggest things to you that many families have found meaningful.

Many parents are comforted by contact with their baby, and there is nothing wrong with wanting to see, hold, and touch them, no matter how far along in the pregnancy you are. Some parents know what they would like to do, even before giving birth. Others cannot make that decision until they have given birth. Some parents decide that they do not want to see or hold their baby at all. Sometimes, one person does not want to see or hold their baby, while another person does. Whatever you decide to do, remember that it is a very personal choice, that you can always change your mind, and that your healthcare team will support you.

If you decide to see or hold your baby, you may decide to hold your baby right after birth, or you may wish to wait a bit before making a decision. Sometimes, parents are scared about how the baby will look or about how they will feel. Some parents are worried that they will be traumatized by seeing their baby. In some families, cultural traditions or spiritual beliefs guide whether or not they will see, hold, or name their baby. Talk to your healthcare team about the options that are right for you. Your healthcare team will be able to support you and your family to arrange for care that respects your wishes, traditions, and preferences.

When making your decision, you may find it helpful to:

- Talk ahead of time about the delivery. Your healthcare team can give you some guidance about what to expect. You may decide to see how things go, and to change your mind depending on how you are feeling. For example, if you are in pain or feeling nauseous, you may ask the healthcare team to keep your baby in a safe place until you are ready to see or hold them. Or, you may ask the healthcare team to describe your baby to you first before you decide if you would like to see or hold them right away. Remember, you can change your mind at any time.
- Ask your healthcare team to take your baby at birth and keep them in a safe place until you are ready to see or hold them. Some families request that their baby is kept in the room with them, while others are ok for their baby to leave the room with a healthcare provider until they ask to have them in the room. Others would like to have their healthcare team describe their baby before they see them, to help them prepare.
- Choose to hold your baby but not see them. Your healthcare team can help you with this. They may place your baby in a warm blanket and wrap them gently, so that you can hold them and spend time with them but not see them.
- Ask your healthcare team to describe your baby to you
- If possible, ask your healthcare team to give your baby a bath before you see them
- Remember that there is no rush. Take as much time as you need. You can also change your mind at any time.

Special Items

Your healthcare team can also assist with collecting special items that will honour and remind you of your baby. Some of these items may include:

- Photographs (pictures)
- Your baby's footprints and/or handprints
- Your baby's identification bracelet
- Information about your baby's birth
- A bassinet card
- A blessing, baptismal, or other ceremonial certificate
- A tape measure to show the size of your baby
- A lock of your baby's hair
- Cord clamp
- Your baby's clothing, hat, or blanket
- Hand and foot molds
- Placenta imprint

Other mementos you may wish to add to your baby's memories package include:

- Poems and notes you may collect or write to or about your baby
- An ultrasound picture
- A certificate of life
- Certificate of death or stillbirth
- Cards

If you are unsure about whether you want to take the items home with you, talk with your care provider before you leave the hospital. It may be possible for your mementos to be kept at the hospital until you are ready to bring them home. Many families who do not initially take them come back for them, sometimes many years later.

Caring for Your Baby

You and your family will be encouraged to participate as much as you wish in the care of your baby after birth. This care may include bathing, dressing, and bundling your baby in a blanket. Your healthcare provider will be available to assist, or if you prefer, your healthcare provider can perform this care alone or with someone you would like to be a part of this care. Talk to your healthcare team about what will work best for you and your family.

Cultural and Spiritual Traditions - In Hospital

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

There may be cultural, spiritual, or other traditions surrounding the naming of your baby. Deciding to name your baby may be a difficult decision, but many parents find this meaningful when their personal wishes and cultural traditions allow for it.

How Long do We Have?

Your baby may stay with you as long as you choose. Once your baby has been taken to the hospital morgue, it is generally possible to have your baby brought back to you to see and hold. Talk to your care team about this process, as it will vary depending on where you live and give birth. Once your baby has been taken to a funeral home, they will also be able to assist you with seeing your baby and spending time with them again.

Stillbirth
Investigations

Stillbirth Investigations

After a stillbirth, many families want to know why it happened. Your healthcare team will likely ask you about doing some investigations or tests to try to determine the cause of your baby's death. These investigations or tests may include blood tests collected from the birthing parent, examination of the placenta, and blood or tissues from the baby being sent for chromosomal analysis.

You may also be offered an autopsy. An autopsy involves an examination of the baby's internal organs and may sometimes identify reasons why the baby died. During the autopsy, the baby is treated with respect and dignity. Depending on where you live and give birth, your baby may need to be transported to another hospital that has the needed staff required for these tests and investigations. Your healthcare team will be able to answer your questions about these processes.

Sometimes, families are too shocked to think about this process at the time of their baby's death. Sometimes, they are worried about what will happen to the baby (i.e. during the autopsy) or worried that the tests will delay important ceremonies or traditions (i.e. burial). Sometimes they worry they will not be able to see their baby again after the tests. Many parents find this overwhelming to think about at a very difficult time. If you feel this way, you are not alone.

However, sometimes some very important information can be gathered from the investigations, such as why the stillbirth happened and what risks a person may have in a future pregnancy. Your healthcare team will discuss the different options available and help you choose a plan that is best for you, your baby, and your family. Remember you can ask as many questions as you wish.

It may help to know that some families will choose some investigations, such as examining the placenta and blood work, but not others, such as an autopsy of their baby. It may also be helpful to know that there are different types of autopsy procedures, such as partial or limited autopsies, where you can choose what procedures are performed.

A limited autopsy allows for an examination of the outside of the baby, x-rays, and testing of the baby's chromosomes, if that is needed. Your healthcare team will be able to explain what is available to you in your community.

In many cases, the investigations will help to rule out certain causes, such as infection or a small placenta, but an exact cause will never be identified. Sometimes, even if the tests or investigations are done, no reason for your baby's death will be found. It can be very difficult to not know "why" a stillbirth has happened. It is important to remember that it is never helpful to blame a parent for a stillbirth.

Follow-Up: Test Results

If you decide to have an autopsy or investigation, talk with your healthcare team about who will follow-up with you about the results and how long they will take to come back. Sometimes, results can take up to 6 months or even longer. You may wish to request that the results are sent to your primary care provider (doctor or nurse practitioner) so you can follow-up with them in their office. You may also ask to book a follow-up appointment with the doctor who discussed the autopsy with you or with your pregnancy care provider (doctor or midwife). If you live far away from where you received care, you can ask if the healthcare provider is willing to speak to you about your test results over the phone, or if you can have the test results with explanations mailed to your home. You may also be able to make an appointment with your local nursing station or healthcare team to discuss the results.

Your healthcare team will be able to help you decide who will best be able to follow-up with you once the results are back. Even if the results come back and no answers or reason for the stillbirth are found, you can use the appointment to discuss how you are feeling (physically and emotionally) and whether there are any more supports that you need.

You may also wish to speak to the healthcare team if you plan to keep the placenta for burial, cremation, or other special ceremonies or traditions. This will ensure that the lab or hospital team knows to return everything after they are finished with their investigations.

Funeral, Burial,
Cremation, or Other
Ceremony or Tradition

Burial or Cremation

Your healthcare provider will discuss with you when burial or cremation is required by law. In Ontario, this is after 20 weeks of pregnancy. Some parents may find comfort in making these arrangements, while others will initially be overwhelmed or horrified. Parents may take a few hours or several days to make decisions about burial or cremation before requesting assistance from a funeral home and/or cemetery. Some families find it helpful to have a close friend or family member assist in making these arrangements.

The cost of burial or cremation varies by community and by company or funeral home. Depending on where you live, you may have several options and find it useful to call around to see if there are major price differences. Some funeral homes offer reduced fees for the cremation and/or burial of babies. If you have a burial, you will likely need to pay for a cemetery site and the opening and closing of the grave. The cost of these services varies by community. For more information, please visit pailnetwork.ca.

How Does my Baby Reach the Funeral Home?

Funeral homes will offer to come to the hospital to bring your baby to the funeral home. There may be a cost associated with this. If you live far away from the hospital, there may already be a process in place for bringing your baby back to your home community. Your healthcare team should be able to assist you with information.

It is also within your rights to bring the baby yourself from the hospital to the funeral home. Some families will choose to take their baby home first, or to a special location, before making plans to get the baby to the funeral home. You may be required to sign a hospital release form if you choose to transport your baby. If this is something you wish to do, talk to your healthcare team.

For families who will return home before any investigations or tests are completed, talk to the hospital to make sure the correct process is in place to have your baby and placenta brought back to you or your community. This is especially important for families who live far away from where they gave birth or the investigations or tests are completed.

The healthcare institution where you are receiving care should provide you with burial and transportation guidelines.

Is a Funeral Service or Tradition Necessary?

For many families a funeral, service, ceremony, or traditional event or practice is a way of remembering and honouring the life and death of their baby. However, unlike burial or cremation, a traditional funeral service or event is not required by law. Some families will choose to have a service, celebration of life, ceremony, or other culturally or spiritually meaningful event, while others will not. Sometimes, families will choose to honour their baby in many ways, such as by writing a poem, lighting a candle, planting a tree, having a community sweat lodge, observing a time of mourning, having a funeral or special service such as a Mizuko-Kuya, or organizing or joining a memorial event.

For families who give birth away from their home community, this process may be more difficult because hospital staff may not know about supports in your home community, you may have to wait until your baby is returned home, costs may be a challenge, or people may not even know that you had your baby and that your baby died. When this happens, sometimes families choose to have a friend, family member, trusted local health or community worker, or elder assist with telling people and planning a funeral service or tradition.

Who Can Help with Arrangements?

The hospital social worker, spiritual care provider, your healthcare team, or your own spiritual, religious, or community leaders can offer information and assistance with burial or cremation. You, or a family member or friend, can directly contact a funeral home of your choice.

Similar to burial or cremation fees, the funeral director will explain your options, including costs, and will help to make the arrangements that you seek. With some religious faiths or because of personal choice, this planning and the arrangements may take place at a religious centre or in a private residence, rather than at the funeral home.

Taking Care
of Yourself

Physical Healing After a Stillbirth

After giving birth, your body will gradually return to a non-pregnant state. You will probably still have bleeding from your vagina, similar to a heavy menstrual period for the first few days, and this will slow down over the next several weeks. It is normal to have some small or infrequent bleeding after this, but you shouldn't have very heavy bleeding after about 2 to 3 weeks.

During this time, it is important that you prevent infection by following the guidelines below:

- Only use sanitary pads while you are bleeding
- Do not use tampons
- Change sanitary pads frequently
- Do not douche

Too Much Bleeding is an Emergency

Consult your healthcare provider or go to the closest emergency department or nursing station if any of the following occur:

- Vaginal bleeding filling one pad an hour (heavier than soaking one pad per hour)
- Vaginal bleeding that does not stop or decrease (slow down) by 2-3 weeks
- Vaginal bleeding or discharge that smells bad or that has large clots (bigger than a plum)
- Severe pain in your abdomen
- Chills or a fever over 38.5°C (101.3°F)

Menstruation

Many people will get a menstrual period in about 4 - 6 weeks after their loss. Talk to your healthcare provider if this doesn't happen, or if you have any other concerns. Many families say that the first period after a stillbirth is difficult emotionally, because it is another reminder of the loss. If you find yourself feeling this way, know that you are not alone.

It is possible to become pregnant after a stillbirth, even before your menstrual period has returned. If you do not want to get pregnant during this time and could get pregnant from sexual intercourse, healthcare providers recommend using birth control methods, such as condoms. Talk to your healthcare team about the option that is best for you.

Milk Production

After the stillbirth, your body will likely start to produce milk. Many people find milk production very sad, cruel, shocking, and distressing, as this is another reminder of your baby that died. Many families describe feeling anger towards their body or the situation, or deep distress that their body is making food for a baby that isn't there. Some families feel pride when they produce milk. Many families feel a combination of things. If you feel this way, you are not alone. After your baby is born, you have several options, and what you decide to do will depend on many factors. Talk to your healthcare team if you have questions.

What To Do: Stopping Milk Production

Many families will decide to stop milk production after their baby is born. The major influence on milk supply is how fully and 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 unrelenting or severe engorgement (filling of the breast/chest tissue).

To alleviate discomfort you may find it helps to:

- If your breasts/chest tissues become firm, gently hand express your milk (gently massage and squeeze your with your hand to remove drops or teaspoons for comfort only) 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'). Immediately after hand expressing/pumping apply cold compresses (described below). Apply cold compresses or a bag of frozen vegetables for 15 minutes. Repeat as necessary every 2-3 hours. To avoid damage, it is important not to apply the frozen items directly to your skin (wrap in a wet tea towel or cloth first). Do not use heat, as this can increase breast/chest tissue swelling and increase your chances of an infection

- If safe to do so, depending on your medical background, take pain medication such as ibuprofen or acetaminophen as needed. Both of these medications may be purchased 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.
- For comfort, wear a comfortable (not tight) fitting bra or top that does not have an underwire. 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 typically ranges 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 assist you as well.

What to Do: Continuing Milk Production and Donating Your Milk

Some parents may decide to maintain 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 to assist another baby in need. In order to become a donor, there is a screening process which typically involves 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 sav-

ing 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.

Follow-up After Your Stillbirth

You will most likely be offered a follow-up appointment (sometimes called a postpartum appointment) with a healthcare provider after the stillbirth. This appointment is usually around 6 weeks after you give birth, but may be earlier if you need closer monitoring (blood pressure check, heavy bleeding, etc.).

The person who you will see for your appointment will vary, depending on where you gave birth and where you live. Sometimes families will want to have follow-up with their primary care provider (doctor or nurse practitioner). Others will have follow-up with the care team that cared for them in pregnancy or for their birth, for example an obstetrician, midwife, or family doctor.

Some families will have both, depending on where they live. At your follow-up appointment(s), you may be asked about or want to talk about:

- How you are doing physically (bleeding, pain)
- How you are doing emotionally (feelings, thoughts)
- Contraceptive options
- Stopping or starting medications (prenatal vitamins, thyroid medications, etc.)
- Ideas for support in your community
- Follow-up (Do you need another appointment? When will you talk about test or blood work results? Autopsy or pathology results? Do you need any further investigations? When?)
- Paperwork needed for time off work, For more information on the available options, please visit pailnetwork.ca.
- Considerations for your next pregnancy (if you would like more information, please see Appendix One – Facing the Future at the end of this booklet)

Grief and Loss: A Lifelong Journey

Many families describe forming an attachment to their baby long before the baby is born. As a parent, your hopes and dreams for your little one likely began when you found out you were pregnant, or maybe even before that, such as when you decided to start trying to conceive. When a baby dies, families often grieve the loss of their baby and the future they imagined. Grief is a normal, healthy, healing, and loving response to the loss of a loved one.

After your baby dies, you may feel deep physical and emotional pain that does not ever go away. We are sorry this has happened to you.

Grief is a natural response to loss and 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. Many families say that even if the pain changes over time, it may become stronger again at certain times, for example when you get your next period, on your due date or baby's birthday, or when seeing another pregnant person, healthy baby, or family with children.

The following may be experienced after a stillbirth:

- Crying and sadness
- Temporary impairment of day-to-day functioning, which means you don't feel like yourself or feel 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 of being alone
- 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

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.

*Dealing
with Emotions*

Does Everybody Feel This Way? Sadness, Shock, Guilt, and Anger

After a stillbirth, 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 due date, on your baby's birthday, or at the start of each school year. Sometimes these feelings seemingly come out of nowhere and surprise you when you least expect it.

Many people feel guilty about their baby's death and constantly wonder '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 'easy' pregnancies or very sad when they know that it was the last time they could 'try' for a baby. Other people feel 'numb' after their stillbirth. If you feel or think these things, you are not alone.

We know that far too often, families feel isolated and misunderstood by family members, friends, co-workers, and care providers. You deserve to have the support you need. If you need more 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
- Doula
- Crisis Support Volunteer or Victim Services Volunteer
- 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 stillbirth, 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 is very common for families who have experienced a pregnancy loss. **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. There is some evidence that the risk for anxiety or depression is higher for people who have experienced a stillbirth.

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 and a loved one may be the person concerned. Maybe you did try to talk to someone about it, but they didn't listen or you felt embarrassed.

Many of the thoughts and feelings associated with stillbirth 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 persistent 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
- Difficulty concentrating
- Thoughts of hurting yourself or others

If you have a personal or family history of mental illness, let your care provider know. 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 your care provider 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 your pregnancy care team 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 be able to provide screening, follow-up, referrals, and supports for you and your family if necessary.

Some families also find it helpful to:

- Reach out for support if you need it. 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 their local Public Health Department. Many Public Health Departments will have nurses or trained volunteers that can help you and tell you about supports in your community.
- Talk to other parents who have experienced mental illness
- Talk to a crisis support line 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 mentalhealthhelpline.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 local services.

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

Grief and Your Relationship

If you have a partner(s), you may find that you each experience grief differently. 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 the loss or them.

In some cases, your partner may feel that they are expected to remain outwardly strong to support you. This can hide feelings of loss and sadness as your partner tries to cope themselves. 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 they can complete their work and tasks.

Partners may also play an important role in telling the other family members (including children) what has happened and what will happen in the immediate future. It is important to discuss with your partner how you will handle questions from children, family, and friends and to discuss how they are coping with this often difficult task.

Many partners say that they feel especially alone and isolated, because friends, family members, and healthcare providers will ask about the parent who gave birth but not them. This can be especially difficult when the partner is struggling with their grief and not getting the support they need.

Many partners say that sexual intimacy after a stillbirth is challenging, especially if one person is ready and the other is not. Sometimes peo-

ple feel ashamed of or disappointed in their body. Sometimes physical symptoms, such as pain, bleeding, or lactation mean that a person does not feel sexual. Sometimes the sadness or anger means that a person can't connect with their partner in an intimate way.

It is important that partners not blame themselves or each other, and to remember that you are both grieving the same difficult loss. Although it may be difficult, it is important to try to be respectful of each other and where each person is on their grief journey. Talking about your feelings and differences with each other can be helpful. Some families also find it helpful to talk with a trusted person, such as a friend, family member, or professional.

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 Two at the end of this booklet.

Special Challenges

Special Challenges

After experiencing a stillbirth, families may face unique challenges including:

Lack of Recognition: Families, friends, and healthcare providers 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.

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.

Sometimes families will hear deeply hurtful things, such as:

- "You are young, you can always try again."
- "Once you get pregnant again, you will feel better."
- "At least you didn't know the baby."
- "At least the baby didn't suffer."
- "Now you have an angel in heaven."
- "What did you do wrong?"
- "I told you something was wrong."
- "Try to be grateful for the children you have."
- "They're in a better place."
- "You chose this..."
- "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 and/or done something to prevent it. They may feel overwhelming guilt if the stillbirth was because of a medical condition with the baby or pregnant person 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 friend. 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. 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 the baby.

Social Isolation: After a stillbirth, many families say they feel alone and isolated. There are few, if any, shared memories and therefore parents may feel they are grieving alone. This may be especially true for families who had to travel away from home for pregnancy care, emergency pregnancy care, or to give birth. Parents may feel anxiety about being asked (or not being asked) about their pregnancy or baby and therefore avoid others. They also may avoid being around other pregnancies, babies, and/or children.

You may also feel alone and isolated because some of your closest friends, family members, or co-workers have hurt you. Maybe they said something upsetting to you, or didn't say anything at all to acknowledge your loss. Maybe in your family, you're not supposed to talk about death or sad things or cry openly. Maybe you are feeling misunderstood by them a lot. Because of this, you might be avoiding talking to or spending time with people who used to be a bigger part of your life. Often, family and friends want to do the right thing, but they may be unsure of how to help or what to say. If possible, let them know how you feel and what you need during this time.

Wondering What Could Have Been: Parents grieve their dreamed upon future, the family they envisioned, and the life that could have been.

Memorializing Loss: Many families experience that there are few, if any, rituals for the loss of a pregnancy or baby. Some families will choose to have a funeral or memorial service or other ceremony, while others will not. Families may not know how to honour their experience,

their loss, or their baby. They may feel deeply hurt that some people don't attend a ceremony, call to check in, or offer support in other ways. They may also feel deeply hurt if they feel people feel it is strange that they are having a ceremony, taking photos, or wanting to talk about their baby or show their photos.

If you are feeling alone and isolated and you want more support, you may find it helpful to talk to your care providers about your feelings. Your care providers may be able to tell you about additional supports in your area. Some people only share their thoughts with their partner, best friend, or perhaps through their journal. Many families also find it helpful to talk to other people who have gone through a pregnancy loss.

PAIL Network provides peer support for families who have experienced a stillbirth. Whatever you decide, the most important thing is that you get support and help when you need it.

Ideas for Support

You and your family are unique, and what you find helpful and supportive might be different than what others find helpful and supportive. Take what is useful, and leave the rest behind.

Some ideas for support 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 healthcare providers
 - 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 pregnancy or baby in a way that is meaningful to you: 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, name your baby, have a ceremony for your baby, wear a special piece of jewelry to commemorate your baby, light a candle, or plant 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 that have had a similar experience. Talking with others can be validating and comforting.
 - 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 assist families with the necessary paperwork.
- For more information on current policies, please visit pailnetwork.ca.

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. There is help and support.

Resources and Support

For an up-to-date list of helpful resources, or to get support, please visit to www.pailnetwork.ca. 888-303-PAIL (7245) pailnetwork.ca

Appendix One

Facing the Future: Pregnancy After Stillbirth

You may find that making decisions about future family planning is difficult at this time. It may take time for you to work through these decisions. You may have already had a discussion with your care providers about this, for example in the hospital when talking about an autopsy or at a follow-up appointment when discussing contraception plans or follow-up tests.

Some families have found it helpful to wait a few months before considering another pregnancy. Others will want to talk about this right away. Some won't want to talk about ever. You may have special considerations to think about, such as timing between pregnancies if you had a c-section delivery, if you have been advised to wait for blood work results or other tests, or if you will need to use fertility assistance for another pregnancy.

If you do want to think about another pregnancy, sometimes thinking about your medical, emotional, and support needs ahead of time will help you to choose the best pregnancy care team and discover what is important for your family in the next pregnancy. You may want to ask yourself:

- Do I want to do pre-conception planning, which means meeting with a care provider to discuss considerations in my next pregnancy? These may be medications to take (aspirin, thyroid medications, progesterone, etc.), blood work to do (to rule out underlying medical issues that can increase your risk of stillbirth), or other tests

or health considerations, such as ultrasounds or support to stop smoking. Depending on where you live, you may be able to meet with an Obstetrician or Maternal Fetal Medicine Physician (high risk pregnancy doctor) to talk about this.

- Do I want to do genetic counseling, which means meeting with experts who will be able to discuss a plan for assessing my risk of genetic issues in future pregnancies?
- Do I require specialty or 'high risk' pregnancy care? This may mean care from a specialist (obstetrician or maternal fetal medicine physician) or care at a hospital with advanced screening and support processes.
- How do I feel about specialty or 'high risk' pregnancy care? If it has been recommended for me, is there anything else I would like included in my care that will make me feel more supported or comfortable? If it has not been recommended to me, am I comfortable with that?
- Who will be my primary care provider in the next pregnancy? (midwife, family physician, obstetrician, etc.) Do I want the same care providers? Different care providers? What is available to me where I live?
- Do I want to request extra appointments, ultrasounds, and screening tests? Or would I like to receive 'routine' pregnancy care if possible?
- Do I have any questions for my pregnancy care team about my past loss? Do I have any questions about how, if at all, that loss will impact my next pregnancy?
- What supports do I currently have in place? What extra supports would I like to explore?
- Are there any other medical issues that I would like to discuss with my care team? For example, a personal or family history of diabetes or depression.

A pregnancy after a stillbirth, or any type of loss, can be a stressful experience both physically and mentally. PAIL Network provides support to families in pregnancies after stillbirth. For example, there is a booklet for Pregnancy After Loss and peer support available. For more information about these supports, please go to www.pailnetwork.ca

Appendix Two

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 7245



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