

Pregnancy After Loss



Pregnancy and
Infant Loss Network

 **Sunnybrook**
PREGNANCY AND
INFANT LOSS NETWORK

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: **pailnetwork@sunnybrook.ca**

Website: **pailnetwork.ca**



Who you can call for help

- ▶ **Your pregnancy care team (doctor, midwife, nurse)**

Phone:

- ▶ **Public Health or Community Health Centre**

Contact the Public Health Department, Best Start Hub, or Friendship Centre in your local community.

- ▶ **Your spiritual care provider, clergy, community leaders, or elder**

Phone:

- ▶ **Local Crisis Helpline**

Phone:

For any non-crisis mental health or illness information, please visit the Canadian Mental Health Association's website (mentalhealthhelpline.ca) or call 1-866-531-2600.

Pregnancy and Infant Loss (PAIL) Network

We are an organization of peers supporting families who have suffered pregnancy and infant loss. We achieve this through education, peer, 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, along with generous donors and dedicated volunteers. To learn more about our support services or to make a donation, visit us at pailnetwork.ca.

Thank You

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

Note: While the information contained in this publication will hopefully give you useful tools and ideas, it is not intended to replace professional health and medical care.

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.



Introduction

What to expect from this booklet

Being pregnant after experiencing a previous pregnancy loss or having a baby die may be a hopeful and exciting yet scary, confusing, and difficult time. This booklet has been written by a group of healthcare professionals with bereaved parents who have experienced a pregnancy after loss. It is the hope of PAIL Network that this booklet will help guide you through your own pregnancy after loss experience.

In this booklet, pregnancy loss or infant death include miscarriage or other types of early loss (such as an ectopic pregnancy or the loss of an embryo), stillbirth, the death of a newborn or baby in the first year of life, and medical termination of a pregnancy. Some families who are newly pregnant might feel uncomfortable reading through the birth and parenting sections to start. Please read through this booklet in whatever way is useful for you.

We hope this booklet helps you understand the following:

- Pregnancy after loss is a unique time for families. No family will experience the pregnancy the same. Please take what is helpful from the booklet, and leave the rest behind.
- You have a right to receive pregnancy care that is knowledgeable, understanding, and compassionate. This means a pregnancy care provider who listens to your concerns and needs and works with you as a member of the team.
- Having mixed feelings and thoughts are normal. You may be looking forward to the pregnancy or scared to acknowledge it. At different times, you may feel excited, sad, happy, or angry. You are not alone in feeling this way.
- Having a subsequent baby may not change any of the thoughts and feelings you have, for example fear or guilt. Support after your pregnancy is important for many families, and thinking about these possible supports during pregnancy may be helpful.



Words, meanings and special terms

Embryo and fetus

These are the early developmental stages of a baby. 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 10 weeks until birth.

Infant death

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

Miscarriage or pregnancy loss

The early delivery or loss of an embryo/fetus, prior to 20 weeks gestation.

Neonatal death

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

Stillbirth

The loss or death of a baby after 20 weeks of pregnancy (or weighing more than 500g at birth) but before the baby is born. It can happen during pregnancy or during birth.

Subsequent pregnancy

In this booklet, subsequent pregnancy refers to a pregnancy after a prior pregnancy loss, stillbirth, and neonatal or infant death.



Starting a new pregnancy

Grief and loss: a lifelong journey

When you lose your pregnancy or 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. Many families say that even if the pain changes over time, it may become stronger again at certain times, for example on anniversaries or when seeing another pregnant person or healthy baby.

For many families who have suffered this type of loss, starting a new pregnancy might mean that their feelings of grief and loss become stronger as they think about their baby that died. You might find it difficult to be excited for your new pregnancy or feel guilty about those feelings. You might feel happy that you are pregnant again or angry that you are pregnant again and that your baby died. It is very common to feel scared as you approach the time in your pregnancy of your previous loss or worried every time you have an ultrasound or test that something will be wrong. You may feel jealous that others who are pregnant have an 'easy' pregnancy and frustrated that you can no longer have a 'normal' pregnancy. You may worry about how you sleep, what you eat, and how much activity you do. Many families feel that every thought and activity in their subsequent pregnancy is impacted by their previous loss.

We know this time can be very challenging for many families. You are not alone in feeling or thinking these things. While feeling and thinking these things is normal, some families have told us that they found certain activities helpful. If you want, you may try:

- Writing a letter to your baby or babies that died. Tell them why you are sad. Tell them that you miss and love them. Tell them that a new baby is on the way.
- Writing a letter to your baby in this pregnancy. Tell them about their sibling. Tell them why you are sad, or excited, or scared.
- Keep track of ways this pregnancy or baby are different than and the same as your previous pregnancy or pregnancies.



Grief and loss: a lifelong journey (cont'd)

- Spend time visiting a special place you have to remember your baby.
- Talk about these thoughts and feelings with your partner, family, friends, or healthcare providers.
- Honour your baby or babies in a way that is meaningful to you: donate to a local charity, do something you enjoy while thinking of your baby, or attend a memorial event.
- Connect with peers: join a support group, read other people's stories, meet with a friend who will listen to you as you talk.
- Instead of having a baby shower/celebration while you are pregnant, have a celebration after the baby is born.

Remember, your needs are unique and you know best what you and your family need at this time. Surround yourself with people who are able to support you and your family.

Feeling alone: isolation in the subsequent pregnancy

In pregnancies after loss, many families say they feel alone and isolated. This may be because you have decided not to share that you are pregnant until you feel you are at a 'safe' time in the pregnancy. This 'safe' time may never come. Because of this, people do not know you are pregnant and you are not able to talk about how you are doing or feeling. You may also feel sad that you are missing out on things that other pregnant people get to enjoy, such as posting a creative pregnancy announcement on Facebook, gifts and celebrations, going to 'normal' prenatal classes, and well-wishes or 'special' treatment.

You may also feel alone and isolated because some of your closest friends and family members have hurt you. Maybe they said or did the wrong thing when your baby died, or said something upsetting when you told them you were pregnant again. 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. Because of this, you might be avoiding talking to or spending time with people who used to be a bigger part of your life.

You may also feel alone and isolated because seemingly everyone else is enjoying their pregnancy. You hear people in the waiting room talking about getting the baby's room ready or strangers in the grocery store say "You must be so excited! I loved being pregnant!" Listening to people complain about morning sickness or stretch marks or lack of sleep with a new baby might make you feel sad and angry and make you feel that you can't say what's on your mind without making people *really* uncomfortable.

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. In some bigger hospitals, there are pregnancy groups you can join. 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 after loss. PAIL Network provides peer support for families experiencing a subsequent pregnancy. Whatever you decide, the most important thing is that you get support and help when you need it.

Different grieving styles

Sometimes the difference in people's grieving styles can cause conflicts in relationships. This can be especially true when the people are close to each other, such as spouses, partners, or close friends and family members.

It is important to mention that there are many different grieving styles or coping mechanisms, meaning that each person responds to and handles loss uniquely. If possible, talk about this with the people who are close to you. Some families find it helpful to talk with their care provider or to talk with a mental health professional.



Sharing the news: telling people you are pregnant

Just like in any other pregnancy, deciding when to tell people you are pregnant is a personal decision that will look different for each family. In pregnancies after loss, many families say they struggle with when to share the news. Some families share very early in the pregnancy, either widely or to a few people. Some families decide to wait for a 'safe' time in pregnancy, sometimes after the timing of their previous loss or after receiving the results of some pregnancy tests. Some families do not know when or how they will share the news and wait until someone asks them or it becomes obvious that they are pregnant. Others only tell people whom they will see, and wait until after the birth to share the news more broadly.

Many families with other children at home worry about telling them about another baby. Sometimes the questions that children ask are difficult to answer and you know that you cannot give them a guarantee. There is no magical answer for the best time to talk about your pregnancy. We hope it helps you to know that you are not alone in struggling through this decision. Some families will find it helpful to ask for help with speaking to their children. Your child's daycare or school teacher may be able to help, or their primary care provider (Doctor or Nurse Practitioner). If available in your area, Child Life Specialists offer psychosocial support for children and assist families in times of change.



Answering *that* question: “Is this your first pregnancy?”

It would be difficult to find a family that has not been asked at some point in their pregnancy, “Is this your first?” Maybe you have been asked a variant of this question, such as “How many children do you have?” While people who ask this question are usually saying, “I notice you are pregnant, and I want to ask you about it”, many do not realize that for some families, this question is difficult to answer. For families who have had a baby die, this question might make them feel sad, angry, guilty, anxious, or uncomfortable.

For many families, their answer to the question depends on who is asking and why. If you are shopping and a stranger asks you, you might decide that now is not the time to share about your baby that died. Or, you might decide to tell them. It may depend on the day. Either is ok.

Many families say that if they do not share about their baby that died, they feel guilty or sad. Some say that even if they decide to share about their baby, the conversation then goes in a direction that makes them feel sad, angry, guilty, anxious, or uncomfortable. People might then ask “Why did your baby die?” and you suddenly find yourself talking about your baby in the frozen food section when you did not want or mean to. Or perhaps you are glad to be talking about your baby. Instead, maybe the stranger does *not* ask how your baby died and that makes you feel sad or angry. You are not alone in feeling or thinking these things.

If possible, many families find it helpful to think about their response ahead of time. You might want to say:

- Thank you for asking, but I do not want to talk about my pregnancy at this time. You can leave out the ‘thank you for asking, but’ part.
- No, this is not my first pregnancy.
- I have had another pregnancy, but that baby died.
- My baby died because he was born early or I don’t know why my baby died.
- I have three children.
- I have three children, but one of them died.



Answering *that* question: “Is this your first pregnancy?” (cont’d)

Many people do not understand how common pregnancy or infant loss is. This lack of awareness or stigma can be very difficult. If possible, try to remember that the person is likely asking to make small talk, and they will most often happily continue on with their day, even if you decline to talk with them. Answer the question however you would like. If one day the question was especially hard for you, or you feel sad or angry or disappointed with how you answered it, it may help to share that with someone, either your partner, a friend, or your healthcare provider.

For many families, this question is especially hard when it is asked by a care professional or provider, such as an Ultrasound Technologist, Physician, Nurse, or Receptionist. All of a sudden, the option to decline to share is taken away. You might even find the same care professional or provider keeps asking you the same question at each visit, and you might wonder how people cannot remember or communicate this with each other.

Many families find it helpful to share their history with the professional or care provider at the start of their visit. For example, you might want to say to the Ultrasound Technologist, “In my first pregnancy, my baby died, so I am very nervous today” or to the Physician, “Appointments make me very nervous because I have experienced a pregnancy loss before”. Some offices or hospitals place special notes or symbols on charts for families who have experienced a loss. It is ok to ask to have one placed on your chart if you would like, and to ask a new care provider or professional, “Will you please review my chart today? There is a special note on the chart about my pregnancy history”. Care professionals or providers should be open to your suggestions on how to make appointments and tests more comfortable for you.



The pregnancy

Your unique needs for care and support

In a pregnancy after loss, many families say that they have special or unique care needs because having experienced the death of a baby or loss of a pregnancy changes the experience of another pregnancy. When the worst has happened, families often say they are no longer able to expect a ‘normal’ pregnancy or ‘healthy’ baby. Many families think about what they want to do differently this pregnancy. Some families wonder if they will be able to prevent the worst from happening again. Many families feel that ‘normal’ or ‘regular’ pregnancy care no longer meets their needs.

As a result, many families turn to the expertise of healthcare professionals to provide answers or solutions or hope. However, too often in pregnancies after loss, families struggle against a pregnancy care system that is not flexible or adaptable enough to meet their unique needs.

In your subsequent pregnancy, it is important that you receive pregnancy care from professionals who are able to appropriately assess, monitor, and address your medical needs. It is also important that you receive pregnancy care from professionals who are able to assess, monitor, and address your emotional and support needs. Some families will want to have pregnancy care from an Obstetrician or Maternal Fetal Medicine Physician, while others would prefer to have pregnancy care from a Family Physician or Midwife.

While it may not be fair or ideal to have to teach others about your needs or suggest care options that you would like, many families find this is necessary. 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 this pregnancy. You may want to ask yourself:

- Do I require specialty or ‘high risk’ pregnancy care? This may mean care from a specialist or care at a hospital with advanced screening and support processes.



Your unique needs for care and support (cont'd)

- 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?
- 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 current 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.
- Would I like to have someone with me at my appointment to help me advocate for my needs during this pregnancy or to help remember information?

Choosing a pregnancy care provider

In a pregnancy after loss, most families will want to choose a pregnancy care provider or team that they trust and that makes them feel comfortable. Some families will choose a different care provider than in their previous pregnancy, finding it difficult to receive care from the same team. Other families will want to choose the same care provider or team that cared for them previously. Choosing what is best for you and your family is most important.

If you live in a small community, or already have to travel for medical care, you might not have a choice in pregnancy care provider or location. If you are advised to have a higher level of pregnancy care, for example by an Obstetrician or other specialist, you may feel disappointed or angry that your choice is more limited.



If you cannot choose a different pregnancy care team, sometimes you can ask to have a different primary provider, for example, a different lead Physician or Midwife.

Some families find it helpful to talk to their potential or chosen pregnancy care provider about their needs, and you might find this helpful as well. Some questions you may want to ask include:

- What will be my plan of care this pregnancy? Will I be seen more frequently? Will I have more ultrasounds and tests? What if I want more ultrasounds and tests? What if I do not want more ultrasounds and tests?
- In between appointments, am I able to contact you or your office if I have any questions or concerns?
- Are you willing to 'share' my pregnancy care with another provider? For example, you may wish to see a Midwife team for the majority of your pregnancy care, with visits at certain times to a Physician or other pregnancy specialist.
- How, if at all, will my care differ from my previous pregnancy care?
- Will I see you for most appointments or does the care team change frequently?
- What if I want to be seen more frequently in this pregnancy? Are you able to arrange for that?
- If needed, do you have any supports to which I could be referred? For example, a Social Worker, Psychiatrist, Nurse, Dietitian, etc.?
- Have you had any specialty bereavement training?
- Is my partner and/or family able to attend appointments with me?
- What will happen if I need to be transferred to a high risk provider or hospital? Is there a chance that my baby will be sent to a different hospital?
- Are you able to provide more postpartum follow-up? If yes, what will that look like?



Choosing a pregnancy care provider (cont'd)

In your early appointments, and as the pregnancy progresses, you will likely want to talk to your care provider about what you are thinking, feeling, and what you need. In the beginning, you might not know what you need, and this is ok. Even if your care provider does not routinely ask you about how you are coping or feeling, it is ok to bring it up with them at your appointments. All care providers will want you to have a healthy pregnancy, and this will mean talking with you about what you need and what you find helpful as the time passes.

Many care providers will be able to refer you to other supports during your pregnancy, either in your community or at a local hospital. You might also want to find some of your own supports. Some examples of additional support include a:

- Social Worker
- Psychologist, Psychotherapist, Psychiatrist, or other mental health professional
- Public Health Nurse or Community Health Nurse
- Child Life Specialist
- Community Centre, Friendship Centre, or Best Start Hub or Resource Centre
- Dietitian
- Spiritual or Religious Care Provider, Community Leader, or Elder
- Lactation Consultant
- Prenatal Educator
- Doula

Monitoring the pregnancy

It is very common for families to request extra ultrasounds and appointments in pregnancies after loss. Sometimes, extra ultrasounds and appointments are recommended to you by your pregnancy care team. For some families, especially those that live in rural or remote areas, extra ultrasounds and appointments are not available or if they are, getting to them may be difficult because of the distance you have to travel or the time it takes to get there.



It is also very common for families to be surprised that extra ultrasounds and appointments do not give the relief or peace of mind that was expected. While many families find comfort in the moment, often the comfort is short-lived. Some families experience more stress and worry leading up to the ultrasound or appointment, which can be difficult if they are happening often. If you experience these things, you are not alone.

Your care provider should understand that many families who are pregnant after loss feel risks to the pregnancy that often go beyond actual medical risk. This means that even if you know or are told that “this will not happen again” or “the last time was an accident and it will not repeat itself” or “there is no evidence that what happened last time will impact this pregnancy”, actually *believing* that this is true is difficult. This is why many families tell us that even if they are told that there was nothing they did to cause the loss, they still avoid certain foods or activities, especially if they believe that their loss was somehow connected. This is also why many families request extra monitoring and earlier delivery, even if their care team says it is not necessary.

If possible, talk openly about this with your pregnancy care team. Ask the team how they know your baby is well. Ask the team about why they do or do not recommend extra monitoring. Ask about extra supports during this time, and tell them if you are struggling and what you think might help.

It is important to remember that while some families will want to have extra pregnancy tests, monitoring, and appointments, some will only want those that are necessary or ‘routine’. These are decisions that are personal, and they should be made in collaboration with your pregnancy care team, who can explain the risks and benefits to you clearly.



Are you having a boy or a girl? Thoughts on finding out the sex of the baby

In a pregnancy after loss, some families hope for a baby that is the same sex as the baby that died, while other families hope for a baby that is a different sex. Many families who did not know the sex of the baby that died have hopes for finding out this pregnancy. Finally, some families do not think about this much at all.

When the baby's sex is revealed, some parents are surprised to discover that they feel disappointed, angry, guilty, or sad. Some parents report feeling like they are having a 'replacement' baby if the sex is the same, while others report feeling a deep sense of sadness and resentment if the sex is different. Some families worry that knowing the baby's sex will now make it much harder if this pregnancy also ends in loss, while others feel angry if they sense a pressure from their family or community for a certain sex. If you have any of these feelings, you are not alone. If possible, talk about these thoughts and feelings with a trusted person.

Attachment: feeling connected to your pregnancy

In a pregnancy after loss, some families look forward to connecting with the baby and feel a sense of joy and excitement as the days pass by. Other families struggle with feeling connected to their pregnancy or baby, feeling distant and finding it hard to believe or purposely trying to avoid attaching. Sometimes, it depends on the day or week.

In a subsequent pregnancy, many families delay or avoid preparing for the baby's arrival. Maybe you can't bring yourself to set up the baby's room or area. Maybe you can't bring yourself to celebrate your baby with family and friends until you know that this time, you will be bringing a baby home. Some families have told us that they don't ask very much about how their partner is feeling because they don't want to get too close again. Maybe you just don't know what or how to ask or what to do.



Families are often able to adopt unique coping styles in pregnancies after loss. You know what is best for you and your family. As they are able, some families find it helpful to:

- Talk about their thoughts and feelings with a trusted person, including the pregnancy care team. Many families find it helpful to talk to other people who have been through a pregnancy after a loss.
- Ask a friend or family member to purchase baby supplies after the baby is born, and bring them to you when you are ready.
- Ask family, friends, and work colleagues to wait until the baby is born before they give you gifts. Or have someone keep the gifts for you and bring them to you after the baby is born.
- Slowly get ready for the baby by purchasing a little at a time, or a few essentials such as diapers, wipes, and one 'going home' outfit.
- Ask a friend or family member to help you set up the baby's room or area. If you already had a room set up when your baby died, some people want to have someone help them make a few changes, or go through their supplies. If you decide to use some of the same items, that's ok. If you decide to get all new items, that's ok too. Do what you need to do.
- Decide that supplies for babies can be quickly purchased and that right after birth, babies do not need a set up nursery.
- Know that if they feel or think or do these things, they are not alone.



Preparing for baby: prenatal classes, tours, and birth plans

Prenatal education or preparation for parenting classes is a common way to get information on ways to have a healthy pregnancy, the birth process, labour and delivery options, and ways to take care of and feed a new baby. The classes are also often a chance to meet other parents, to ask questions from an expert about things that worry or concern you, and to have a tour of the place where you will give birth.

For many families who are pregnant after loss, preparing for birth is difficult. Many families do not attend prenatal education or preparation for parenting classes, even if they want to. Some families do not think that they will fit in in a ‘normal’ prenatal class, or they wonder if the content will cause worry or distress. Some families worry they will say something that scares the other parents, feel angry that other people seemingly don’t think about the fact that babies die, or they might not want to ‘jinx’ the pregnancy by assuming there will be a baby to take home. For some families who had their baby die later in pregnancy or after birth, they may have attended classes before and not feel like they want to attend again.

All families deserve to have access to information that will support them in making decisions about their pregnancy and birth, the opportunity to ask questions, and support in caring for a new baby. While you may not feel comfortable attending regular prenatal classes, some families find other ways to prepare, such as:

- Asking their local prenatal education department or program for one-on-one classes (or classes for their family).
- Attending regular classes, but speaking to the Educator ahead of time so they know their history and fears and concerns.
- Doing the classes online. Many Public Health Departments or Best Start Hubs will have free online prenatal class options, or information that you can research on your own time about pregnancy and parenting. The Public Health Agency of Canada has information on a healthy pregnancy, including emotional and mental health.



- Getting information from family members, friends, or books.
- Asking your pregnancy care team for information and supports.
- Asking the hospital or birth centre for a private tour. Many families find it helpful to see the space where they will give birth ahead of time. For some, this is a very difficult process, especially if they are returning to the same space where their loss happened. Take along a trusted person with you, and tell the person doing the tour about what happened to you. Even though it is very difficult, many families say it helps to relieve some of the concerns they have about returning back to the same space. For some families, it is very helpful that the first time back is not when they are there to have the baby. If you are on 'bed rest' or unable to take the tour in person, ask to arrange for a virtual tour.
- Creating a written birth plan. A birth plan is a document that tells your care providers your story, your preferences for birth and care of the baby, and any other information that you feel is important. If you think it will help you to have your thoughts and wishes written down, ask your care provider to assist you with starting a birth plan. If possible, review it with the pregnancy care team and talk about it with your support people ahead of time. You can find more information about birth plans, as well as birth plan examples at www.omama.com. Search for 'making a birth plan'.
- Talking to the Neonatal or Pediatric Team where you will give birth.
- Arranging a meeting with a Lactation Consultant to discuss infant feeding options, questions, goals, and your feelings.
- Talking to the staff that provide care for you after the baby is born. Let them know your concerns and ask them your questions. If possible, have another person with you to listen to the teaching. Ask for written instructions, if you find this helpful.
- Arranging for help at home after the baby is born. Sometimes this can be from family, friends, your partner, or a healthcare professional, such as a Public Health Nurse.



Does everybody feel this way? Worry, fear, and vulnerability

Many families experience worry, fear, stress, anger, sadness, guilt, and vulnerability in their pregnancies after loss. Sometimes these feelings are connected to a certain event, such as the time before an ultrasound appointment, sitting in a waiting room with other pregnant women, talking to friends who just don't understand your experience, waiting to feel the baby move when you wake up in the middle of the night, or an anniversary or the time in your pregnancy when your baby died. Sometimes these feelings seemingly come out of nowhere and surprise you when you least expect it.

Many families worry that something they do or don't do will cause harm to their pregnancy or baby, even if they have been told that it will not. Many people feel guilty about their pregnancy loss or baby's death and constantly wonder 'if only'. This can make the current pregnancy very stressful. Sometimes families worry that they won't be good parents or that they won't know how to take care of their baby. Many families worry that they are bothering their partner or family or friends or pregnancy care team with questions or that people will think that they are constantly overreacting. Unfortunately, sometimes families are told this. 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, and care providers. You deserve to have pregnancy care and support from a team that provides a safe space for you to discuss your feelings and thoughts. If you need more support, talk to a trusted person, including your care provider.



Beyond worry: anxiety and depression

During pregnancy, it is normal for people to have thoughts and feelings that range from happy and excited to worried and sad. For families who have had a previous pregnancy loss or had a baby die, having these thoughts and feelings is very normal. Many of these thoughts and feelings come from grief, which is very common for families who have had a baby die.

Sometimes, certain thoughts and feelings can be a sign of mental health problems such as anxiety and depression. Having anxiety or depression means more than having a bad day or a scary thought. Anxiety and depression during pregnancy can happen to anyone. There is some evidence that for families who are pregnant after loss, the risk for anxiety or depression is even higher.

Diagnosing and treating anxiety and depression during pregnancy 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 while pregnant is so difficult that people are not comfortable talking about it. The pressure to be happy and excited for the pregnancy can make it 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 parent. Some people are worried about being forced to take medication. Maybe you did try to talk to someone about it, but they didn't listen or you felt embarrassed. Finally, many of the thoughts and feelings associated with pregnancy 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.



Beyond worry: anxiety and depression (cont'd)

Talking to your pregnancy care team about mental health is important. 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. Ask your care provider to ask you about your mood at your appointments, 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 and finding it difficult to cope. 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:

- Connect with their local Public Health Department, Healthy Babies Healthy Children Programs, Aboriginal Healthy Babies Healthy Children Programs, Best Start Hub, or Friendship Centre. Many Public Health Departments will have Nurses or trained volunteers that can support you at home. They will also be able to tell you about supports in your local community.
- Talk to other parents who have experienced mental illness.
- Join a support group.
- Talk to a mental health professional.
- 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.



Birth and parenting

Birth

Some families who are having a baby after a previous loss are excited and looking forward to the birth. Some families are scared and worried and sad when thinking about the birth, especially if it makes them think about the baby that died or if their baby died during or shortly after birth. Many families experience a mix of emotions. Some are surprised about their thoughts and feelings, especially if they thought they would feel differently. Some families have chosen a different type of birth than before. Others have suffered an early pregnancy loss and are experiencing many new things. For some families, this is the first time they are back in the same hospital or area where their loss took place. All of these things can be stressful and sad. They can even cause or bring up past trauma.

For many families, knowing this is normal and common is reassuring. Sometimes it is helpful to know that some parents who thought they would be scared and sad end up feeling confident and happy when their baby is born. Sometimes it is helpful to know that some parents who thought they would be confident and happy end up feeling scared, sad, or guilty when their baby is born. If this happens to you, it is normal, and doesn't mean you love one baby more or less than the other. Grief is a complicated but normal response to loss, and it often accompanies happy occasions when you think about what has been lost. As much as is possible, be kind to yourself.

Although it can be very difficult at times, many families find it helpful to share what they are thinking about and feeling with their birthing team. Your pregnancy care team will be able to answer your questions and talk to you about what to expect, especially if you will have a labour induction or caesarean birth (C-section). Some families find it helpful to write out or talk about what most scares or excites them, or what they want to be different this time. Some families find it helpful to share about their loss with the birth team, so everyone present can know about the whole family.



Birth (cont'd)

This can be spoken about, or written in a birth plan document (for more information on a birth plan, please see section 'Preparing for Baby'). It's also ok to say "I'm not sure how I'm going to feel". Some families bring something special to the birth that represents the whole family, including something to represent or honour their baby who died.

Postpartum care

After your baby is born, just like any new parents, you will need care, support, and information. Many families who have a baby after a previous loss feel worried, scared, and vulnerable and need lots of advice and reassurance. They wonder if they will be able to take care of a new baby and what will happen if something goes wrong. Maybe you didn't believe you would ever have a baby and you don't have any supplies. Maybe it's been difficult to communicate with your family or friends during the pregnancy and now you aren't sure who to call for help. Maybe your baby died after birth and you are only starting to worry now. Many parents worry that their bodies won't make enough milk or that they won't know if their baby is eating enough. Maybe you feel really sad or angry. If you think or feel these things, you are not alone. Most families find it helpful to talk with someone.

Your pregnancy care team will listen to your concerns, answer your questions, give you information, and refer you to helpful supports. Some families find it helpful to ask:

- How do you know my baby is doing well?
- What are some warning signs I should watch out for (for both myself and baby)?



- For infant feeding, is there a class or clinic I can visit? Are you aware of any ongoing supports? How do I know if the baby is getting enough? Will my body make enough milk? How do I safely prepare formula?
- Are there any supports you can refer me to once I go home? Would any Hospital or Public Health Programs be a good fit for me? (Healthy Babies Healthy Children, Aboriginal Healthy Babies Healthy Children, Early Years Centre, Best Start Hub, Breastfeeding Clinics, Friendship Centre)
- Who do I call if I have an issue or question once I go home?
- Do you have any written materials I can take home?
- What follow-up appointments should I make for the baby or myself?

Parenting

Some families say that a previous pregnancy loss or death of a baby impacts the way they care for another baby or how they parent other children. Some families report feeling guilty, scared, angry, or constantly worried. Some families say that they are always worried something bad is going to happen or that they will not be able to keep their baby safe. Some parents report feeling guilty when holding their new baby, thinking that the only reason why they are holding that baby is because another baby died. Families are told “at least you have a healthy baby now” or “you must be so happy” or “you really need to relax”. Some parents want to talk about their baby who died but no one asks. Sometimes families feel that people assume they have ‘moved on’. Sometimes this makes parents feel misunderstood or very angry or sad. As a result, it is sometimes difficult to ask for support from people, especially if they are people who are making hurtful or insensitive comments. Because of this, many families again find themselves alone and isolated.



Parenting (cont'd)

Just as it is normal for your previous loss to have impacted your pregnancy, it is normal for it to impact how you parent. When possible, be kind to yourself and surround yourself with people who are understanding and willing to listen when you talk. Some families find it helpful to:

- Talk with other families who are parenting after loss. PAIL Network provides support for families.
- Talk to professionals such as Social Workers, Psychologists, Psychotherapists, Nurses, Midwives, or Physicians.
- Join a community group, for example through the local Public Health Department, Best Start Hub, Early Years Centre, or Community or Friendship Centre.
- If you gave birth to multiples (twins, triplets, etc.), reach out to your local multiples group.
- Use wellness checklists. In Ontario, parents have free access to the Nipissing District Developmental Screen (www.ndds.ca), which is a tool to track development for infants and children up to 6 years of age.
- Ask family and friends for help at home with things like cooking, cleaning, and childcare while you get to know your baby.
- Ask your primary care provider (Physician, Nurse Practitioner, Midwife) to see your baby more frequently at the start, while you gain confidence and trust in your parenting abilities.



Family and friends

Partners

In a pregnancy after loss, some partners report feeling more connected to the pregnancy and feeling that they want to be more involved. They might wish to:

- Attend more pregnancy appointments
- Ask more questions
- Be home more
- Talk about their thoughts and feelings
- Make more decisions and share their opinions

Other partners report feeling less connected to the pregnancy and feeling that they want to avoid involvement or attachment. They might wish to:

- Avoid pregnancy appointments
- Avoid asking questions about the pregnancy
- Work more hours or stay away from home
- Avoid talking about their thoughts and feelings
- Make few decisions and keep their opinions to themselves



Partners (cont'd)

In both cases, partners may feel worried and scared or happy and excited, or a mix of different emotions. Often, in subsequent pregnancies, families feel alone or isolated. For partners, this may be especially true because they may be expected to support their partner and not upset them or may not be asked how they are doing. They may be hesitant to trust clinicians or feel overwhelmed caring for other children. We know that in pregnancies after loss, partners may have unique needs and require special support. For example, they may need more support from friends, family, and care providers. Some partners find it helpful to talk to other parents. PAIL Network provides partner support. They may also find it helpful to speak with their primary care provider (Physician or Nurse Practitioner) about their mental health needs, or to take the opportunity at pregnancy appointments to ask the pregnancy care team *their* questions.

Siblings or other children

In a pregnancy after loss, parents are often concerned about their other children. They may ask themselves:

- When do we tell them about the new pregnancy?
- What if this pregnancy also ends in loss?
- How do I answer their questions or reassure them?
- Am I paying enough attention to them?
- Why am I so nervous that something bad will happen to them too?
- Why don't they seem to care about the new baby?
- Should I cry in front of my children or show them that I am sad?

If you are thinking or feeling these things, you are not alone. Many families find it best to be open and honest with children, and to use explanations that are clear and simple and appropriate for their age. Try not to make promises about things you can't control.



Some families will find it helpful to tell children about what to expect and to give them a special role in the pregnancy and after the baby is born. It may be helpful to ask family and friends to help with things such as childcare or special outings for other children. Sometimes, families find keeping a routine for children is helpful. Your child's primary care provider may also assist you with ideas on how to support them. Talking to other parents with children who have experienced a loss may also be helpful.

Family-centred care

In a subsequent pregnancy, grandparents and close friends often experience excitement, worry, fear, and sadness. During your pregnancy, some family members or friends may relive their own subsequent pregnancies and as a result, behave differently towards you. Many times, they want to be included in pregnancy care. For some families, involving others is an easy and wonderful experience. For other families, involving grandparents and close friends is a difficult and stressful experience.

You know what is best for you and your family, and what will be helpful and supportive. Talk to your pregnancy care team if you want your pregnancy care to include partners, siblings, grandparents, and friends in appointments, teaching sessions, and discussions about fears and concerns.

Resources

For an up-to-date list of helpful resources, or to get more information or support, please go to pailnetwork.ca.





1-888-303-PAIL (7245)

pailnetwork.ca

PR 47508 (June, 2017)