A Difficult Choice: A Booklet for Families Ending a Pregnancy

Pregnancy and Infant Loss Network

Sunnybrook
PREGNANCY AND INFANT LOSS NETWORK

A Difficult Choice:
A Booklet for Families Ending a Pregnancy

"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: pailnetwork@sunnybrook.ca

Website: pailnetwork.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:

About Us

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

PAIL Network is able to offer its services 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 the advice and care of professional healthcare providers.

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 the families who reviewed this booklet and who shared their experience for the benefit of others.

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

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.

What you'll find here

Introduction

What to expect from this guide

Bereaved parents and healthcare professionals created this booklet to guide you through what to expect when faced with a difficult choice to interrupt or end a pregnancy. While there are other reasons why a person may choose to end a pregnancy, this booklet was created for all families who are faced with the decision because of issues with the health of the baby or babies, because of a risk to the health of the pregnant person or pregnancy, or because of other life circumstances where a pregnancy cannot continue. In Ontario, you may hear words like 'abortion', 'termination of pregnancy', 'life-limiting diagnosis', 'abnormality', 'fetal reduction', 'labour induction', or 'pregnancy interruption'. We will talk about what all these words mean in this booklet. No matter the reason that your pregnancy is ending, this may be a very difficult time in your life, and we want you to know that there is help and you are not alone. We are deeply sorry that you are experiencing the death of your baby or end of your pregnancy.

You may have many questions about what to do around the time your pregnancy ends. Reading this booklet can answer some of these questions. There are many different reasons why a family decides to stop or interrupt a pregnancy. This booklet covers several of those reasons. This booklet covers several of those reasons, which may or may not be relevant to your situation. Please read through this booklet in whatever way is useful for you.

Everyone's loss is unique and families express emotions in a way that makes sense to them. Through the many families we have supported, we have heard some commonalities in what these families reported experiencing. We hope that the information provided in this booklet helps you navigate through the physical and emotional challenges that may happen to you. We hope this booklet also helps you to better understand the 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 the end of their pregnancy, including shock, sadness, shame, guilt, anger, and self-blame. If you feel these things, you are not alone.

- After your pregnancy ends, you may feel deep physical and emotional pain. Many families say that over time, the pain may come and go at different times, and soften. When a family is faced with a problem in a pregnancy and they must make a difficult choice to end the pregnancy early, recognized to be a decision made with considerable love, they may wonder if they made the right decision. They may worry that their decision was wrong, or question if they knew enough information, or doubt the healthcare team that was giving information at the time. They may have felt rushed, or that they were expected to make an impossible decision.

- After a baby dies or a pregnancy ends, many families wonder if there is something that they did to cause the problem or something they did to cause the baby to be sick or to have to be born early, such as when a cervix opens early and an infection means a family may have to decide to stop the pregnancy before the baby will be able to survive, for the health of the pregnant person. A person may feel ashamed of their body or feel that it 'failed' them. Families may think, "If only I did…" or "If only I didn't do…" or "If only I had done…". If you feel or think these things, you are not alone.

- When a family is faced with a difficult pregnancy decision, they may begin to question beliefs or feelings they have. They may question if there is good in the world, or why bad things happen to good people. They may find it hard to continue to believe in a God or higher power or feel that what they have always believed is no longer true. A person may struggle with beliefs they have always held, and no longer know who they are or what they believe. Or, they may feel closer to a God or higher power, or their spiritual community. People may also feel shame or guilt and may not be able to tell people in their lives everything about the situation, for fear of being judged or shamed.

- Many pregnancy problems happen for complex, complicated, sudden, or unknown reasons. At other times, losses are because of a difficult choice that families must make. Whatever the reason may be, 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 dies after 20 weeks of pregnancy. For some families, it will be important to make decisions long before 20 weeks of pregnancy, while for others, it will be important to wait until after 20 weeks of pregnancy. Your healthcare team will be able to explain the differences and help you to make a choice that takes your preferences into account. 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 pregnancy loss or baby's death stays with a family forever. Although the supports you need will likely change over time, you may find that for the rest of your life you have times where your grief is more significant and times where your grief feels very manageable. This is normal.

Words, meanings, & special terms

Abortion
Abortion is a medical term used to describe when a pregnancy is removed from the uterus, usually during the first 19 weeks of pregnancy. During an abortion, pregnancy tissue, products of conception, a baby (fetus), or the placenta may be removed from the uterus. The terms used may depend on how far along the pregnancy is. For example, you may hear professionals say 'embryo' before 11 weeks of pregnancy, and 'fetus' after 11 weeks of pregnancy. The word abortion is most commonly used for pregnancies that are stopped under 20 weeks gestational age. A pregnancy can be stopped after 20 weeks gestational age, although typically the medical terminology changes from 'abortion' to other words (termination of pregnancy or TOP), stillbirth, etc.).

In Canada, there are two main uses of the word abortion. The first is used to describe a therapeutic abortion, which is when an abortion is started or induced by a medication or procedure by choice or on purpose.

You may also hear this type of abortion described as an elective abortion, induced abortion, pregnancy interruption, or termination of pregnancy. Most people are thinking about this type of abortion when they hear the word. The second main use of the word abortion is called a 'spontaneous abortion', and this is the medical term for a miscarriage.

A spontaneous abortion happens when a pregnancy ends because of natural causes. There are different types of miscarriage. If you have more questions, please speak to your healthcare provider, or request PAIL Network's booklet "Miscarriage: Pregnancy Loss Before 20 Weeks".

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) and Dilation and Evacuation (D&E)
Short surgical procedures during which the cervix is opened (dilated) and tissues from the pregnancy (i.e. placenta) are removed from the uterus. You will be given pain relief for the procedure.

A D&C is generally used when the pregnancy is under 14 weeks gestational

age, while a D&E is used when the pregnancy is over 14 weeks, as the baby is larger and different processes may need to be used.

For both the D&C and D&E, the goal is to remove all the pregnancy tissues. Both the D&C and D&E are done in an operating room and in most cases you can go home on the same day as the procedure.

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

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.

Fetal Abnormality
This term may be used by a healthcare professional to describe a structural or chromosomal issue with a baby. For example, an ultrasound may find that the baby has a structural problem with their heart, spine, brain, or kidneys. Or a blood test may find that the baby has an extra chromosome, such as in Down Syndrome (Trisomy 21) or Edwards Syndrome (Trisomy 18), or another genetic disorder. Sometimes these 'abnormalities' can be fatal (sometimes described as 'not compatible with life'), life-threatening, or life-changing. You will likely have many questions for your healthcare team if you hear these words. This is normal.

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.

Genetic Condition or Disorder
A genetic condition or disorder is a genetic problem caused by

one or more abnormalities with a person's genes or chromosomes. Sometimes genetic disorders are found before a baby is born, and sometimes they are not. Sometimes genetic disorders impact how long a person will live and whether or not they will have any health problems. You may hear people talk about a 'spectrum'. This means that there may be big differences between how a genetic disorder may impact different people. Genetic disorders are complicated and complex. Your healthcare team will be able to answer your questions and arrange for you to meet specialists with knowledge about genetic disorders (genetic counsellors), if necessary.

Genetic Counsellors
Genetic counsellors are health professionals with special training and knowledge in the areas of medical genetics and counselling. Genetic counsellors help families to understand genetic disorders and how they may impact a pregnancy and their baby's life, so that they can make informed medical and personal decisions. Genetic counsellors may explain options for prenatal testing or diagnosis, and help to interpret test results.

Gestational Age
Completed weeks of pregnancy measured from the date of a person's last menstrual period. For example, you may hear someone say that "I am 25 weeks pregnant". This means they are 25 weeks gestational age.

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.

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

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

Miscarriage
The early delivery of a baby (embryo or fetus) or loss of a pregnancy

prior to 20 weeks gestational age. The medical term for a miscarriage is a 'spontaneous abortion'.

Misoprostol
A medication (drug) that may be prescribed to start labour (make the uterus cramp or contract (tighten)).

Multifetal pregnancy reduction (MFPR) or Selective reduction (SR)
Multifetal pregnancy reduction is a procedure used to lower the number of babies (fetuses) in a multiple pregnancy. You may also hear this described as a 'fetal reduction'. In a MFPR or SR, a person is pregnant with more than one baby, and they make a decision to lower the number of babies that they will continue the pregnancy with. For example, a person pregnant with triplets may reduce the pregnancy to twins, or a person pregnant with twins may reduce the pregnancy to a single baby. This is most often done to lower the risk in a pregnancy with more than one baby, or if there is an issue with one of the babies (for example, a genetic disorder). The most common way a selective reduction happens is through a procedure where medication is used to stop the heartbeat of one baby, but not another.

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

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.

Products of conception
A medical term to describe the pregnancy tissues formed in the uterus after conception until 20 weeks gestation (e.g. yolk sac, placenta, amniotic membranes, embryo, or fetus).

Stigma
Stigma is often defined as a 'mark of disgrace', something negative that changes how people think about or treat something or someone. Often the negative belief is unfair or untrue. Stigma can take away from a person's reputation or mean that a person experiences discrimination, because of something negative that is believed to be true about them. Abortion or ending a pregnancy carries a lot of stigma.

Stillbirth
In Canada, the birth of a baby who is born without any signs of life at or after 20 weeks of pregnancy or weighing more than 500 grams at birth, if under 20 weeks gestational age. The baby may have died during pregnancy (called intrauterine death), labour, or the birthing process (but before they were born).

Termination of Pregnancy
A medical term that includes both surgical and non-surgical ways of ending a pregnancy.

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.

Why are some pregnancies stopped?

Why are some pregnancies stopped?

There are many reasons why a family may choose to end a pregnancy, and many different ways that people will feel during this time.
For some families, making the decision to stop a much-wanted pregnancy will be the hardest decision they will ever have to make. They may feel angry, sad, overwhelmed, or shocked. For other families, they may feel relief that stopping a pregnancy is an option. Many people feel both sadness and relief.

Problems with the baby

Sometimes a pregnancy is stopped because of a problem with the baby. You may hear the words 'fetal abnormality'. This term may be used by a healthcare professional to describe a structural or chromosomal issue with a baby. For example, an ultrasound may find that the baby has a structural problem with their bones, heart, face, brain, or kidneys. Or a blood test may find that the baby has an extra chromosome, such as in Down Syndrome (Trisomy 21) or Edwards Syndrome (Trisomy 18), or another genetic disorder or problem. Sometimes these 'abnormalities' can be fatal. You may hear the words 'life-limiting diagnosis' to describe a problem with the baby that will likely mean that the baby will die during the pregnancy, or shortly after birth. Not all problems with a baby are life-limiting. Even if they are not life-limiting, some problems with a baby will be life-changing, both for the baby and their family. At other times, an ultrasound may find that a baby is not growing properly in a pregnancy, or has another problem. You will likely have many questions for your healthcare team if you discover that there is a problem with your baby. This is normal.

Problems with the pregnancy

Sometimes a pregnancy is stopped because of a problem with the pregnancy. For example, sometimes the fluid around the baby (amniotic fluid) is very low, because the membrane is broken too early or because the placenta isn't working properly. Sometimes a person is pregnant with more than one baby, and they decide to lower the number to lessen the risk that the pregnancy won't be healthy, or that the babies will be born too early to survive. This process is known as a multifetal pregnancy reduction (MFPR) or selective reduction (SR).

Problems with the health of the pregnant person

Sometimes a pregnancy is stopped because of a problem with, or risk to, the health of the pregnant person, and the timing of stopping the pregnancy means the baby will die. For example, sometimes a person needs to start chemotherapy, their blood pressure is dangerously high, or they have a major infection. While this decision will always be difficult, there may be times where this decision must be made urgently, making it even more challenging for families in the moment. No matter what, you will be able to talk to the healthcare team about your questions. If you or your family had to make an urgent decision, you may wish to ask to speak to the healthcare team after to go over what happened and to ask any questions you still have.

Other life circumstances

Sometimes a pregnancy is stopped because of personal reasons. For example, a person may not continue a pregnancy because of the status of their relationship, their personal safety, finances, or the decision that the pregnancy is not at the right time in their life.

Making a decision

Making a decision

No matter the reason why your pregnancy may end, you will likely have many questions for your healthcare team. In addition to your primary care provider (family physician, nurse practitioner) or pregnancy care provider (family physician, midwife, obstetrician), you may find that you will have many extra appointments and see lots of different care providers and professionals. Some of these care professionals may include:

- Women's health clinic staff
- Geneticists or Genetic counselors
- Maternal Fetal Medicine Physicians or Perinatologists
- Obstetricians
- Pediatricians or Neonatologists
- Sonographers
- Nurses
- Social Workers

You may also hear about and be offered many different tests, screenings, or procedures. Some of these may include:

- Extra ultrasounds
- Non-invasive prenatal testing (NIPT)
- Amniocentesis
- Chorionic villus sampling (CVS)
- Magnetic resonance imaging (MRI) (for baby)
- Echocardiogram (for baby)
- Genetic counseling or testing (for parents)
- Multifetal pregnancy reduction or selective reduction

It is important that you are able to have your questions answered during this time. It may help to have support people with you to listen to the information being provided and to ask questions or to write things down. Some families describe being in shock and finding it difficult to remember everything that is being said. Although it may 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 or pregnancy. You may also want to ask for a copy of all your notes and tests, or whether the hospital or clinic has electronic systems that you can join to see all your tests and notes.

Uncertainty

Many families say that even when they have spoken to all the right professionals and had extra testing or procedures, they are still left with difficult decisions or uncertainties. Families may wonder if the testing is accurate, especially when they heard different results or opinions through the process. They may have been told that their baby's condition is on a spectrum, meaning that how it will impact their baby after they are born is not clear, and that they must make a decision not knowing the final answers. Families may read information or hear stories that are confusing, and feel like the choice they must make is an impossible one. Or, they may wonder if the person who is pregnant is really as sick or at risk as they are being told they are if they continue the pregnancy. If you feel or think any of these things, you are not alone.

A note about the '20 week mark'

In Ontario, when a baby is born after 20 weeks gestational age, there are different legal requirements for families and healthcare providers, such as registering the birth or death. There are also legal burial requirements that do not exist for babies born under 20 weeks. Some families who are stopping a pregnancy will want to have everything done before 20 weeks, to avoid having to legally bury or cremate the body, or to complete paperwork about their baby's death. For other families, it will be important to discuss the distinction with their healthcare team because they will want to purposefully wait until after 20 weeks to deliver, if safe to do so.

We have heard from families who did not know about the '20 week mark', and who regret decisions about timing that they made. Many healthcare providers assume that all families will want to be as quick as possible, and may not consider that for some families, they will want to make it past 20 weeks of pregnancy. There is no right or wrong answer. Please speak to your healthcare team, who will be able to discuss your options and help you decide what is right for your family. It is also important to know that even if you haven't reached 20 weeks in your pregnancy, you may still choose to bury or cremate your baby (there just isn't a legal requirement to do so).

Some families will also be able to access time off work, either through their workplace (sick time) or governmental policies, such as pregnancy

leave or personal emergency leave. Although what people are eligible for will vary, some families who deliver within the timeframe of 17 weeks before their due date (so after 23 weeks gestational age) will be able to access pregnancy leave. This may be another reason to think about timing of delivery. For more information, talk to your healthcare provider, human resources department, or visit the relevant Government of Ontario or Canada website.

Changing care providers

For some families, there may be a need to change pregnancy care providers during this process, or to have other care providers closely involved in their care. For example, a family that has chosen a midwife for their pregnancy care may start seeing an obstetrician, or a family that has been followed by a professional in their home community may have to travel to see a different specialist or go to a different hospital. Meeting new people during this time, or being labeled as ‘high risk’ or ‘complex’ may be difficult and stressful for some people. Even if your original care provider will be able to stay involved in your care, for example for support or follow-up purposes, you may still feel sadness about this change. If you feel this way, you are not alone.

How will it happen? An overview of the processes

Introduction – Medical and surgical interventions

Once you have decided to stop your pregnancy, your healthcare team will be able to discuss all possible options, and help you understand the differences between them. In some cases, your healthcare providers may decide what methods or processes are best for you. This may depend on your health history, how far along you are in your pregnancy, and where you live (what is available in your community). It will also be helpful for your healthcare team to understand what is important to you throughout the process, such as having your family present, being as fast as possible, being able to do an autopsy or pathology exam, or holding or seeing your baby (if possible, depending on how far along you are in your pregnancy). In some cases, you will be asked what you would like to do. If you are given a choice, there are several factors you may wish to consider.

Remember: there is no wrong choice. If you are given a choice, choose the method that feels right for you and your family. Talk to your health-care team about what options are best for you, including the risks and benefits of each management method. Discuss your thoughts, feelings, questions, and concerns with your healthcare team. Although it may be difficult, many families find that the process of discussion with your healthcare provider will help you to feel involved in your care and more in control.

There are two main methods typically offered to families. They are:

- **Medical interventions:** Medication is used to help the body pass the pregnancy. What medication is used and where it happens (at home or the hospital) depends on different factors, including where you live, how far along you are in the pregnancy, and your specific set of circumstances (health history, preferences). Depending on how far along you are in the pregnancy or where you live, you may be able to take the medication at home or in your local community. It may also be a faster option than waiting for surgical management, if there is a long wait for operating room time. Your healthcare team will be able to discuss this with you.

Some things to consider:
Depending on how far along you are in your pregnancy, a medical intervention may be more likely to provide you with the opportunity see and hold your baby, if you would like. It may also make it easier

to collect samples for testing in a lab, or to do an autopsy, if that is important to you or recommended by your healthcare team. Your healthcare team will be able to help you to decide what is best for your situation.

- **Surgical interventions:** A surgical procedure (either a D&C or D&E) is done at the hospital or other specialized clinics. During the procedure, your cervix is opened and the doctor uses special tools or suction to remove the baby and pregnancy tissues. You are given medication so that you do not feel pain during the procedure. Very often, families will go home on the same day as the procedure. There are few side effects from surgical intervention, but people may have to wait for a spot in the hospital to have the procedure done or travel a long distance to a location that is able to provide this service.

Some things to consider:
Depending on how far along you are in your pregnancy, a surgical intervention may make it less likely that you will be offered the chance to see and hold your baby, although you can always ask to do so. Your healthcare team will be able to speak with you about what you can expect to see. Surgical interventions may also make it harder to collect samples for testing in a lab, for example, testing a placenta that is ‘complete’ or ‘whole’, or to do an autopsy. Your healthcare team will be able to help you to decide what is best for your situation.

KCL

What is KCL?
Potassium chloride (KCL) is a medication that is sometimes used to stop a baby's heart before they are born. A medical term that is sometimes used for this process is "induction of fetal demise".

Why is it used?
KCL is used for two main reasons. The first is for a procedure called a multifetal pregnancy reduction or a selective reduction. We talk more about this below. The second reason is for a procedure commonly used in the second trimester (weeks 13-28) when there is a plan to end a pregnancy during this time, so that when the baby is born, they are not born alive.

What does the process look like?
Using an ultrasound to help guide the doctor, they will insert a long needle through the abdomen of the pregnant person. Most commonly, the needle is then placed into the baby's heart, or the fluid around the baby, and the KCL is injected, causing the heart to stop. Another ultrasound after the procedure will confirm that the heart has stopped beating. Usually after this procedure, a plan will be made to medically or surgically end the pregnancy.

Will this be offered to me?
There are many factors involved in the decision to use KCL in the process, and whether this is offered to you may depend on:

- Where you live, and if the needed professionals or equipment are available
- How far along you are in the pregnancy
- The type of intervention you are planning (medical or surgical)
- Your preferences
- Timing (it will be less likely to be offered if there is an induction for an urgent health issue for the pregnant person, such as an infection or very high blood pressure, and more likely if there is a planned induction for a problem with the baby)

Your healthcare team will be able to discuss this more with you, and answer your questions.

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

Assisted reproductive technology (ART) and fertility drugs and assistance have made pregnancies with more than one baby (twins, triplets) more common. When a pregnancy involves two or more babies, the risks of complications, such as miscarriage, stillbirth, preterm birth (and death), and lifelong disability increase with each additional baby. In a MFPR or SR, a person is pregnant with more than one baby, and they make a decision to lower the number of babies that they will continue the pregnancy with.

For example, a person pregnant with triplets may reduce the pregnancy to twins, or a person pregnant with twins may reduce the pregnancy to a single baby. The goal of this procedure is to increase the chance of a healthy pregnancy for you and the healthy survival of the remaining baby, by lowering the risks in a pregnancy with more than one baby. This procedure may also be used if there is an issue with one of the babies, but not the other (for example, a genetic disorder).

The most common way a selective reduction happens is through a procedure where medication is used to stop the heartbeat of one baby, but not another. You may also hear this process described as a 'fetal reduction'.

The procedure

In Canada, a selective reduction is most often done through the belly, or abdomen, of the pregnancy person (trans abdominally). The doctor uses an ultrasound as a guide and inserts a needle through the pregnant person's abdomen and into the uterus and water membrane (gestational sac). A solution is then injected to stop the heart. The solution works immediately. This procedure is most commonly done during the first or early second trimester. Because the baby is very small during the first trimester, as the pregnancy progresses, the demised baby is usually absorbed by the pregnant person's body, meaning you will likely not be able to see the baby after delivery.

After

Some people may experience vaginal leaking of fluid or bleeding after the procedure. Please let your healthcare team know if you experience these symptoms, and talk about what to do if they start after you are sent home after the procedure. Although the risks are low, MFPR can sometimes lead to infection, preterm labour, and miscarriage. Please discuss the risks and benefits of a MFPR with your healthcare provider.

The decision to have this procedure can be a difficult one. Those who experience selective reduction may find it challenging to cope with the loss as your pregnancy continues. You may also find it challenging when you see or hear about other multiple pregnancies, or get asked by others about your pregnancy history, including health professionals. You may feel guilt, shame, grief, and sadness, even if you feel confident that you made the best decision for yourself and your pregnancy. If you feel or think any of these things, you are not alone.

Medical Interventions

Medical Interventions

Your healthcare team may offer you the option to take medication to end the pregnancy. Depending on how far along you are in the pregnancy, you may be given the option to go home and take the medication, or to take the medication and stay in the hospital. The option to take medication at home is most often offered to people under 13 -15 weeks of pregnancy, but it isn't always limited to this time frame. For most people who are stopping their pregnancy, they will not have had all the information they need to make the decision by this time-frame, so most medical interventions will be in a hospital or clinic, because they will be beyond the 13-15th weeks of pregnancy. Sometimes taking medication is faster than having a surgical procedure, especially if there are long wait times for operating room times. Your healthcare team will be able to tell you if this is the case in your community.

Some common medications used are Mifegymiso ('the abortion pill') (earlier pregnancies) or oxytocin (later pregnancies). Mifegymiso is made up of two separate medications that you swallow (one of the medications is misoprostol). Your healthcare team will give you instructions on what to do and answer your questions. Some people will take misoprostol alone, which comes in tablet (pill) form and is most commonly inserted into the vagina, although it can also be swallowed. Misoprostol may be given to people who are planning to go home during the process or who are staying in the hospital. Oxytocin is given through an IV, so a person needs to be in a hospital or clinic to safely have this medication. Sometimes, people will need to have other processes before they are offered medication, such as techniques to help your cervix get 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. Remember you can ask as many questions as you would like, and ask for details or explanations more than once.

These medications cause the uterus to contract (cramping, contractions), which causes your cervix to open. This helps the pregnancy to pass. The medications take different times to begin working. Cramping or contractions can begin as soon as half an hour after taking misoprostol and almost always within the first 12 hours. While it will be different for everyone, most people who take medication to end their pregnancy will have the process finished in a few hours to days (often at most within a week, for earlier pregnancies). Some people who take misoprostol will have chills, fever, nausea, vomiting, and diarrhea. Many people will have few or no side effects. Your healthcare team will be able to discuss with you whether or not there are medications to help with the symptoms, if you have them.
If you take medication to end the pregnancy, the goal is to have you pass all the pregnancy tissues through the vagina. The experience varies between pregnancies and is affected by the size of the baby and the length of the pregnancy. People who are very early in their pregnancy (less than 7 weeks) will likely find the process to be similar to a heavy period, with no obvious passing of remains. The further along a person is in a pregnancy, the more likely they are to notice tissue or remains. Very heavy cramping or contractions and a feeling of needing to go to the washroom (have a bowel movement) may be felt just before passing of remains. Knowing this signal may help you to prepare. Vaginal bleeding and cramping or contractions can happen at any stage of pregnancy, meaning you may have pain even if you are not far along in your pregnancy.

While the medications we discussed above often work very well, in some cases the medications don't give strong and regular enough contractions to open your cervix and help all the pregnancy tissues to pass. For example, sometimes the baby will pass but the placenta stays inside for longer than your healthcare team feels is safe for you. If this happens to you, the healthcare team taking care of you will talk to you about what to do next. Some people will need different medication, more time, or surgical help.

Pain management

At home
Your healthcare team will be able to speak to you about pain management options, which will be different depending on how far along you are in your pregnancy, where you deliver, your health history, and your preferences. Many families, especially those who are early on in their pregnancy or going home for the process, report that they did not speak to their healthcare team about pain management. This may be because of a false belief that early pregnancy losses do not feel very painful to people, which many families have reported is not true. If your healthcare team does not bring it up with you, it is ok to ask. It is also ok to ask about what to do, or where to go, if the pain becomes too much for you. Having a plan may help you to feel more comfortable and more in control.

In hospital
You will most likely be offered some sort of pain management when you are in labour, which may include medications. 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, including medication options. 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.

You may be offered pain medication by mouth, as a needle (injection), or through your IV. You may be offered a PCA (patient controlled analgesia) pump. This pump allows you to be in charge or your own pain relief, through an IV. 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, or an epidural. Sometimes, people are offered more than one pain relief option throughout the process.

Support people

Whether you are going home or staying in the hospital for this process, many families say it is helpful to have a support person present, or someone close by to call if you need help, company, or other support.

Monitoring

At home
If you are going home through the process, talk to your healthcare team about what to expect, what is normal, and when you should seek care again, either in an emergency (too much bleeding) or for follow-up (to make sure all the pregnancy has passed).

In hospital
While you are in the hospital, your healthcare team will watch your blood pressure, pulse, and breathing (vital signs) and your 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.

Self-care check in:
Take a deep breath

Surgical Interventions

Surgical Interventions

Your healthcare team may offer you the option to have a surgical procedure to end the pregnancy. Surgical interventions to end a pregnancy are usually an option until 21-22 weeks of pregnancy, depending on where you live. If you are talking to your healthcare team about a surgical intervention, you may hear about a D&C or a D&E.

Dilation and Curettage (D&C) and Dilation and Evacuation (D&E)

Both a D&C and D&E are short surgical procedures during which the cervix is opened (dilated) and tissues from the pregnancy (i.e. placenta, embryo/fetus/baby) are removed from the uterus.

A D&C is generally used when the pregnancy is under 14 weeks gestational age, but it isn't always limited to this time frame. A D&E is more often used when the pregnancy is over 14 weeks, as the baby is larger and different processes may need to be used. What is offered to you may depend on where you live, your ultrasound results (size of your baby) and what professionals are available. A D&E requires more specialty training, so people may need to travel a little bit for the procedure if it is not available in their home hospital or community.

For both the D&C and D&E, the goal is to remove all the pregnancy tissues. The entire procedure usually takes about 15-30 minutes. Both the D&C and D&E are done in an operating room or specialty clinic and in most cases you can go home on the same day as the procedure, after being monitored for a few hours when the procedure is finished. You will be given pain relief for the procedure. What type of pain medication you are given, and whether you are 'awake' or 'asleep' for the procedure may depend on where you live, and your health history. You may feel cramping during and after the procedure, which may last for several days. You may also have bleeding from the vagina for days or weeks after. Depending on where your procedure is done, you may have an ultrasound before, or after. Your healthcare team will be able to give you instructions for follow-up, if necessary.

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. Remember you can ask as many questions as you would like, and ask for details or explanations more than once.

Possible Locations

Families report having very different experiences, depending on where they had their D&C or D&E. For many families, where your procedure happens will depend on where you live, what is available to you, and how far along you are in your pregnancy. Where you go, who is around you, and how 'secretive' everything feels can really vary.

Some families will have their procedure in a hospital. Hospitals often have long wait times for OR spaces for these procedures, so families may be offered another option. Other options include a clinic (like a 'Women's Health Clinic') that offers multiple services, including D&Cs, or a clinic that mainly offers procedures to end pregnancies (commonly known as abortion clinics). Some families report being shocked that this is where they need to go, and feeling like the process makes them feel like they are doing something 'wrong' or 'criminal'. Families may have to see protesters, or go through procedures like leaving their bags and phones at reception and being separated from their support people. All of this can make a difficult and often emotional time feel even harder.

It may help to talk to your healthcare team ahead of time, to better understand where you need to go, what will happen, and what you can expect to see or do. You can also sometimes check out the website of the place you are going ahead of time.

Special considerations: Memory making

Depending on how far along you are in your pregnancy, it is important to think about whether or not you want to have some memory making time, such as seeing and holding your baby. This is most often possible after 16-18 weeks of pregnancy because of the baby's development, but sometimes may be possible before this time-frame Although it is always your choice and you may always ask to do so, surgical interventions may change how the baby looks and make it less likely that you will be offered this or want to see the baby. For this reason, if this is important to you, please tell your care team as medical options may be better for you.

A third option: Continuing the pregnancy (Palliative care or Hospice)

A third option: Continuing the pregnancy (Palliative care or Hospice)

You may hear the words ‘palliative care’, ‘palliative management’, or ‘hospice’ used to describe an option that some families choose when their baby is diagnosed with a life-limiting condition that will likely mean that if the baby is born alive, the baby will die shortly after birth or only live for a short time. When this is known in advance, sometimes families will want and be able to choose perinatal hospice or palliative care planning. This may mean families choose to continue the pregnancy until labour occurs on its own or there is another urgent reason to deliver the baby. Perinatal hospice may be chosen for many reasons, including religious, spiritual, or cultural beliefs, or because of other personal feelings and preferences.

When a family chooses perinatal hospice or palliative care, they will meet a care team that will discuss their options and what services they can offer, both for the remainder of the pregnancy and after the baby is born. If this is something you are interested in exploring, please let your healthcare team know. Perinatal hospice and infant death is not covered any further in this booklet. For more information, and for resources on perinatal hospice or infant death, please go to PAIL Network’s website and request a booklet.

Your choice: Memory making

When a pregnancy ends in loss, many families will choose to create memories, both at the time of the loss, and after. There is no right or wrong choice. If you are interested in making memories, this section may be helpful to you.

Options

While there may be some differences in what is available to you, depending on how far along you are in your pregnancy, where you live, and how you deliver, you always have a right to think about what is important to you and your family around this time.

Early pregnancy (1st & early 2nd trimester)

When a pregnancy ends in the 1st or early 2nd trimester (before 18 weeks), options like photographs and hand and foot prints may not always be possible, but there are still other memory making activities you can take part in. Even if your pregnancy ends early, you can still see, hold, and touch your baby or pregnancy tissues, if you would like, and take photos. If this is something you feel strongly about, talk about it with your healthcare team. Some families know that no matter what, they would like to do this. Other families appreciate having a healthcare provider explain to them what they will see, or what they will be looking at, before they make a decision. It is important to remember that even though you do not have a legal requirement for burial or cremation when a pregnancy ends under 20 weeks gestational age, you may still choose to do so. Some other ideas for memory making include:

- Keeping an ultrasound picture
- Writing a letter to the baby
- Creating a special document with information (date, name, support people present, etc.)
- Choosing a special symbol to remember the pregnancy or baby, such as a butterfly
- Planting a tree or flowers
- Donating to a special cause
- Speaking to a spiritual care provider, elder, or community leader
- Collecting cards or other items that remind you of your pregnancy or baby
- Selecting a piece of jewelry or other memento
- Attending a memorial event
- Lighting a candle in memory of your baby
- Starting a special ritual in honour of your baby
- Holding a special ceremony or event

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

Later in pregnancy (2nd trimester & beyond)

There are many memory making options that you may be offered. There are no right or wrong decisions at this time. Some families know that they want to make memories no matter what. Other families will rely on the healthcare team around them to suggest options and to guide them with what is possible. It is ok to ask your care team to guide you through this time and to suggest things to you that other families have found meaningful.

Seeing and holding your baby

After delivery, you may be offered the opportunity to spend time with your baby, if you choose to do so. This option is more likely to be offered to you if you have a medical induction, and the further you are along in your pregnancy (after 16-18 weeks), although this option does not have to be limited to these factors. 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. 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.

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. Some hospitals will have access to something called a 'cuddle cot', which is a special cot used for babies who have died, to help to keep them cool when they are not being held. A cuddle cot may make it possible for you to spend more time with your baby, or for your baby to stay in your room with you for longer. Ask your healthcare team if you can access to this, if this is something that is important to you. Even if a cuddle cot is not available, the team may be able to get you a bedside bassinet where your baby can stay when you are not holding them, so that you are able to have as much time as you would like with them.

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

- Talk ahead of time about what to expect. You may decide to see how things go, and to change your mind depending on how you are feeling or what the healthcare recommends. For example, 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, to help you to prepare. Remember, you can change your mind at any time.

- Choose to hold your baby but not see them. Your healthcare team can help you with this. They may place your baby in a blanket and wrap them gently, so that you can hold them and spend time with them but not see them.

Some other ideas for memory making include:

- Taking and keeping photographs, including ultrasound pictures
- Making hand and foot prints or moulds
- Bathing and dressing your baby
- Keeping blankets, hats, or clothes
- Writing a letter to the baby
- Creating a special document with information (date, weight, name, support people present, etc.)
- Choosing a special symbol to remember the pregnancy or baby, such as a butterfly
- Planting a tree or flowers
- Donating to a special cause
- Speaking to a spiritual care provider, elder, or community leader
- Collecting cards or other items that remind you of your pregnancy or baby
- Selecting a piece of jewelry or other memento
- Attending a memorial event
- Lighting a candle in memory of your baby
- Starting a special ritual in honour of your baby
- Holding a special ceremony, funeral, or event

If you deliver in a hospital, and are unsure about whether you want to take the items home with you, talk with your healthcare team 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.

Post-Loss

Cultural and spiritual traditions

Some families will want to keep cultural traditions or have a special ceremony together, such as a baptism, cedar bath, burial, funeral, or blessing. Depending on the type of ceremony, it can take place now, or in the future when you are ready. You may also wish to include other people, such as siblings, grandparents, special friends, or community members. If you are in a hospital, there may be chaplains or spiritual care providers that can come to see you, or the staff may be able to arrange for someone to come in to see you, including someone from your own spiritual or cultural community, if you wish.

Some families may not know what cultural or spiritual traditions surround the loss of a pregnancy or death of a baby, especially when it may not be seen by their community as 'natural'. Some families describe experiencing stigma, or feeling shame, guilt, and judgement from their cultural or spiritual community. Some families may feel angry, and question their spiritual or cultural beliefs. There may be details you do not share with everyone, which may make having support from your cultural or spiritual communities difficult. For some families, they will learn that there are different 'rules' or procedures that don't apply to them if their loss is from a medical or surgical pregnancy interruption, such as burial, naming, or ceremonial rituals. This may make decisions difficult, and make people feel isolated during an already difficult and lonely time.

For other families, they will feel closer to their cultural and spiritual communities during this time, and find great comfort in tradition and ritual. There are no right or wrong ways to feel during this time.

Remains

What you decide to do with your baby's remains is a personal choice. For many families, this will be the first time they have thought about something like this, and they may not know what to do. For some people, their religious or cultural background will help to guide them at this time. Your healthcare team will be able to discuss your options with you, and support you in connecting with spiritual care leaders,community leaders, and elders so you can discuss what you would like to do. For some families, there will also be some legal requirements, such as burial or cremation.

Burial, cremation, and registration

Your healthcare team will discuss with you when burial, cremation, and birth or death registration is required by law. They will also help you to understand the forms you need to complete, and will give you the information required to complete any necessary forms. There are provincial requirements to register the live birth or stillbirth, and to bury or cremate, any baby that is born:

- At a gestational age of 20 weeks or greater, regardless of weight
- Under 20 weeks gestational age, but over 500 grams in weight

Some people may find comfort in making these arrangements, while others will initially be overwhelmed or horrified that this must be done. People may take a few hours or several days to make decisions about burial or cremation before requesting assistance from a funeral home or service and/or cemetery. Some families find it helpful to have a close friend or family member assist in making these arrangements.
It is important to know that even if you have not reached 20 weeks in pregnancy, or your baby does not weigh 500 grams or more at birth, you may still choose to have a burial or cremation (even though it is not legally required), or a ceremony.

The cost of burial, cremation, or ceremony varies by community and by funeral home or service. 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 services 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.

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 kuyō, or organizing or joining a memorial event.

For families who deliver 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 your pregnancy ended or 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 once they return home.

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.

Autopsy, investigation, or examination of pregnancy tissues

Your healthcare team may recommend an autopsy, investigation, or examination of your baby or pregnancy tissues. This means looking at your baby or placenta or pregnancy tissues closely after delivery. These investigations or tests may include blood tests, examination of the placenta, and tissue samples that may be sent for chromosomal analysis. Sometimes, tissue samples are taken and assessed microscopically in a lab. Sometimes, samples are taken from the baby or pregnancy tissues and tested for genetic disorders or other issues. Your healthcare team will be able to help you understand what options are available and what investigations, if any, you would like done. Depending on how far along you are in your pregnancy, you may be offered an autopsy. An autopsy involves an examination of the baby, including their internal organs. During the autopsy, the baby is treated with respect and dignity. If you wish, this examination can be limited to the organs of most concern. If you do not want a full autopsy performed, you may want to consider something called a 'limited autopsy'. This allows for an examination completed on the outside of the baby's body, including x-rays and testing of the baby's chromosomes. An autopsy may also confirm the sex of a baby.

Whether or not testing or an autopsy is offered or available to you may depend on different things, such as how (surgically or medically) or where it happened (home, clinic, hospital), how far along the pregnancy was, whether you have had any other testing in the pregnancy, and the reason why the pregnancy is ending. Examination requires collection of the pregnancy tissues, which is not always possible. Collection of tissues is easier at some times over others, for example, during surgical intervention (D&C) and when the pregnancy is farther along. Not every clinic, hospital, or community will offer these services or have them available. Even if your community does not have the services locally available, they may have a process in place for testing in another location. Your healthcare team will talk to you about whether an investigation is possible or necessary. After, you will get to decide if it is the right choice for you and your family.

Sometimes, families are too shocked to think about this process at the time their pregnancy ends. 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). Many parents find this overwhelming to think about at a very difficult time. If you feel this way, you are not alone.

However, it is important to know that some very important information can be gathered from the investigations, such as whether a genetic problem with the baby is likely to repeat itself in future pregnancies, whether any issues that were suspected during your pregnancy are confirmed, or 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.

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 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.

You may also wish to speak to the healthcare team if you plan to keep the baby or pregnancy tissues 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. For families who deliver out of their home community, or who will return home before any investigations or tests are completed, talk to the hospital or clinic to make sure the correct process is in place for transportation. 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 will help you to plan for burial and transportation guidelines.

Collecting remains at home

If you are at home, some people will choose to collect the baby or pregnancy tissues, or have been asked to by their healthcare team for testing or assessment. If you are collecting for testing, ask your healthcare team whether there is a special container you need and how to ensure the container gets to where it needs to for testing. If you are not planning to collect for testing, how you manage the remains is a personal choice. Some people will not want to collect them, while others wish to collect them for burial, cremation, or other special traditions. If you wish to collect them, have a small container or box ready. You may want to use a bowl of clean water to wash the remains and avoid using toilet paper or tissues that may stick when handling the remains. If you are seen by a healthcare professional ahead of time, you may wish to ask for a container. Most hospitals will have a collection aid for the toilet, such as a ‘urine or toilet hat’ or ‘urine meter’ that you can ask for.

Taking Care of Yourself

Taking care of yourself

No matter the reason why your pregnancy is ending, it may be a difficult time. You may find it helpful to:

- Rest as you are able. Don't put pressure on yourself to lead your "normal" life during this time.
- Have someone at home or in hospital to help you and to sit with you
- Eat or drink in small amounts (if medically able to do so)
- Get help with child or pet care, making meals, and housework

Physical healing
After your pregnancy is over, your body will gradually return to a non-pregnant state. We have heard from families that during this time, they feel sadness, anger, and shame. Maybe several months later you still 'look' pregnant. Maybe you still need to wear your maternity clothes when you return to work. Maybe you have dark lines or marks from your pregnancy that are there to remind you of what you lost. Having physical reminders of your pregnancy when it is over can be very hard. If you feel this way, you are not alone. Many people will have bleeding from the 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. Some people may have little to no bleeding, and this can be normal as well.
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), for more than 2 hours
- 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 (belly)
- Chills or a fever over 38.5°C (101.3°F)

Milk production
Milk production (breastmilk) is possible after your pregnancy ends, but is most common for people who reach at least 15-16 weeks of pregnancy. Many people find milk production very sad, cruel, shocking, and distressing, as this is another reminder that your pregnancy has ended. Many families describe feeling anger towards their body or the situation, or deep distress that their body is making milk. Some families feel pride when they produce milk. Many families feel a combination of things. If you feel any of these emotions, you are not alone.

If your body is producing milk, you have several options, and what you decide to do will depend on many factors. Please talk to your healthcare team if you have questions.

What to do: stopping milk production
Many families will decide to stop milk production. 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 people may decide to maintain their milk supply. Some people will also wish to explore the process of pumping their milk and donating it to a Human Milk Bank to assist another baby in need. If this is something you are interested in, 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 and to learn about the process. In Ontario, there is one milk bank, based in Toronto. They accept donations from all around the province. Some parents have also found other options meaningful, such as saving and storing frozen milk in the home or having a piece of jewelry or other type of keepsake made by companies that specialize in this type of service (making jewelry out of breast milk).

Medical follow-up
Before you start the delivery process, or right after, you may wish to speak to your healthcare team about plans for following up. Your healthcare provider may arrange for you to have an ultrasound or blood work to make sure everything is complete and all tissues from your pregnancy are gone. You may also be offered a follow-up appointment (sometimes called a postpartum appointment) with a healthcare provider after your procedure or delivery.

This appointment is usually around 6 weeks after, but may be earlier if you need closer monitoring (blood work, ultrasound, blood pressure check, have heavy bleeding, etc.). The person who you will see for your appointment will vary, depending on how your pregnancy ended, how far along you were, 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 procedure, 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 (birth control) options
- Stopping or starting medications (prenatal vitamins, thyroid medications, etc.)
- Ideas for support in your community
- Follow-up (Do you need another appointment? Autopsy or pathology results? Genetics? 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 & Loss: A Lifelong Journey

Grief and Loss: A Lifelong Journey

Grieving the end of your pregnancy is important, and is likely a different experience than grieving other losses in your life. Many families describe dreaming of having a family, and forming an attachment to their baby long before the baby is born. As a parent, your hopes and dreams for a baby may have begun when you found out you were pregnant, or maybe even before that, such as when you decided to start trying to conceive. Even if your pregnancy was unplanned, you may have begun to attach to the baby or pregnancy. When a pregnancy ends, no matter the reason, many families 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. You may mourn for your pregnancy loss or baby deeply, a little, or somewhere in between. You may also feel relief at times, even when you are deeply grieving.

Grief surrounding a pregnancy that is stopped can be very complicated. Stigma may also impact how a person grieves, and how they are treated by others. Some families say that feelings of guilt and shame make it harder to reach out for support, or to give yourself 'permission' to grieve. People may feel like they don't deserve support, because they 'chose' this, or feel that people are judging them or not understanding or acknowledging their loss because of the circumstances surrounding how the pregnancy ended. People may think, "Isn't this what you wanted?" and be less likely to show compassion. Some people have told us that they grieved the person they were before the loss: your innocence may be gone, your beliefs and values may be challenged or changed, and you may not be able to live life in the same way. Families may also worry that they won't be accepted in support groups or that others will feel like their grief isn't as valid. Although it is changing more now, very often people who had losses because of pregnancy interruption were not included in pregnancy loss supports. Even if they are included, people may not feel like they want to share the 'whole story' or reason for the loss, but feel angry or sad that they need to hide this. Coping with these thoughts and feelings, whether your own or from other people, on top of coping with your loss, can be very difficult.

No matter the reasons for your loss, grief is a natural response and deeply personal, which means that everybody grieves differently. Some people move through it more easily, while others are deeply affected. After your pregnancy ends, there is no right or wrong way to feel or grieve. Grief is a process that can be affected by many other life events, and it can change over time, come in waves, or come back when you least expect it. 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. Families have described the following experiences after the loss of their baby:

- 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

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

After a pregnancy ends, 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 pregnancy, 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 pregnancy ending 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 pregnancy ends. Some families have told us that after their pregnancy ends, what they care about changes. The definition of a bad day or crisis changes for them, and it can be hard sometimes to listen to other people complain about their lives or about things that seem silly now. 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 organization
- Peer support organization such as PAIL Network. You can self-refer by filling out the Request for Support form at pailnetwork.ca

Beyond Worry and Sadness: Anxiety and Depression

After a pregnancy ends, 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 or death of a baby.

Grief is not an illness
Sometimes, certain thoughts and feelings can be a sign of mental health problems such as anxiety or depression. Having anxiety or depression means more than having a bad day or a scary thought. Anxiety and depression can happen to anyone. There is some evidence that the risk for anxiety or depression is higher for people who have experienced a pregnancy loss or the death of their baby.

Diagnosing and treating anxiety and depression is very important, but some things make it harder for families to get the supports and treatment they need. Sometimes feeling sad, negative, angry, or anxious is so difficult that people are not comfortable talking about it. It may be hard for people to believe that someone will understand how they feel. Often people feel ashamed that they are having these thoughts or feelings or are worried that people will think they are a bad or weak person. Some people are worried about being forced to take

medication. Some people might not even notice how they are feeling 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. Maybe you feel that you don't deserve support or that you should be punished for what happened.

Many of the thoughts and feelings associated with pregnancy loss 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 connexontario.ca) has information about free mental health services in Ontario and links to mental health service providers and organizations. On their website, you can search for 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 (dial 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 themself. 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 pregnancy ends is challenging, especially if one person is ready and the other is not. Sometimes people 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 a pregnancy ends, 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 pregnancy 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?"*
- *"What's wrong? Isn't this what you wanted?"*
- *"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 and may wonder if they made the right or best decision. They may feel overwhelming guilt. 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 a pregnancy ends.

Social isolation
Pregnancy loss is often referred to as a "silent loss", when families feel as though they cannot share their grief. Many families say they feel alone and isolated. This may be especially true for families who interrupt a pregnancy. 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 or testing and delivery. Parents may feel anxiety about being asked (or not being asked) about their pregnancy or baby or what happened and therefore avoid others. They also may avoid being around other pregnant people, 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 the word 'abortion' carries stigma in your community. 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. Some families will choose to continue to do something on a special date, such as their baby's birthday or the anniversary of their loss, while others will not. Families may not know how to honour their experience, their loss, or their baby, especially when they are keeping details private or when they know that there will be judgment or stigma from family, friends, and their community. 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 grieving or wanting to talk about their pregnancy or baby. 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.

Some families have told us that they find the anniversary of their baby's death or when their pregnancy ended very difficult, especially the first one. Feelings that may have calmed a bit may come back stronger. Families have said they found it helpful to plan ahead for this time. Maybe you would like to take the day off work, if possible. If you have a partner, it may be helpful to talk to them about what you would like to do, if anything. It may also be helpful to talk to friends and family, and to let them know how you would like to be supported during this time.

PAIL Network provides peer support for families who have experienced a loss from pregnancy interruption. 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 pailnetwork.ca or call 1-888-303-PAIL (7245).

Appendix One

Facing the Future: Pregnancy after pregnancy interruption
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 it 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 talk about considerations or plans for testing or monitoring 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 in a pregnancy), or other tests or health considerations, such as early 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? Is there an option to see more than one care provider, if necessary or desired?For example, some families will want to have a midwife and a high risk pregnancy doctor care for them in a future pregnancy, and many places will 'share care', meaning a family can see one care provider (i.e.midwife) for most of their pregnancy visits, and a high risk pregnancy doctor for check-ins or some of their visits.
- 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 pregnancy interruption, or any type of loss, can be a stressful experience both physically and mentally. PAIL Network provides support to families in pregnancies after loss. For example, there is a booklet for families and peer support available. For more information about these supports, please go to PAIL Network's website.

Appendix Two

Children's Grief
After a pregnancy ends or a baby dies, many parents are concerned about their other children and how they will tell them, if they knew about the pregnancy. Families may also be concerned that even if they didn't know about the pregnancy, they may see that their parents are sad or upset, and ask questions that are difficult to answer.

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 PAIL Network's website.

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

Pregnancy and Infant Loss Network

Sunnybrook
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