# PERINATAL LOSS: Losing a baby







## Losing a baby

You have suffered an unimaginable loss and we are so sorry. No words will be able to take away your pain... Losing a child, whether during pregnancy or after the birth, is something that we never imagine happening, which makes this type of loss particularly painful. Perinatal loss is also often misunderstood by society, which can make the grieving process more difficult for you.

This booklet will hopefully help you find appropriate resources to help you grieve, normalize the emotions you may feel and help you navigate throughout this difficult time, knowing that you are not alone.

# What makes this type of loss "different"?

As a society, we all understand that death is a part of life, but none of us expect to lose a child during pregnancy or just after birth. Whether you have suffered a miscarriage, had to make the extremely difficult decision to end your pregnancy, had a stillborn baby or a baby die shortly after birth, you may experience "disenfranchised grief".

"Disenfranchised grief" means that you are mourning the death of your baby, but you feel that you cannot talk about it or share your feelings because it is considered unacceptable to others. Many people will not understand that even if your baby was not born yet, you were already attached to your child and had included him or her in your life plans. In the case of a stillbirth, some people may have difficulty understanding that babies can die prior to labor.

Unfortunately, because others are not comfortable with the topic of perinatal loss, you may have a hard time talking about your grief to them, which makes the grieving process more difficult and painful. You may not receive the same care and attention as you would have if a loved one had passed away in your family.

#### What can be done?

Although nobody will be able to say, do or fix this, it is important to be able to talk about how you are feeling with someone you can trust and who cares about you: a friend, a family member or a professional. There are also support groups with other parents who have experienced the same type of loss. What is important is that you have the chance to work through your grief in a safe space.

# The first few days and weeks

At the beginning, you simply try to cope, get by and survive: you are in "survival mode" and it is important that you take the time to care for yourself. Here are a few suggestions:

- Treat yourself as if you are in need of comfort and care You have just been through a very traumatic experience, physically and emotionally. Even if you would like to go back to "normal life", focus on your basic needs such as resting and eating well.
- Ask someone to take calls and contact people Many will try to reach out and see how you are doing. You may not feel like answering calls, texts or emails. Ask a family member or a friend to answer questions for you. And remember, it is okay to say that your baby died; you are letting others know that this does happen and that it is affecting you at the moment, as any death would affect a person.
- Let your body lead you We all react differently to grief; some may not be able to move or think while others may keep busy and remain active. Listen to what your body is telling you.
- Have someone near you If possible, have your partner, a family member or a close friend be nearby. Let that person help you make decisions, hear your fears and concerns and be a shoulder to lean on

# Coping with friends, family and co-workers

Pregnancy loss can be an awkward subject for many. Explaining your loss to others can leave you feeling drained and angry, especially if some people make thoughtless or unkind remarks. Once you are ready to talk about your loss, you need to have listeners who will make you feel loved and valued. Sometimes people may not realize how upset you are and will either avoid the topic or make hurtful remarks. Others may be truly helpful, by offering to bring a meal for example. Feel free to ask for help.

Sometimes comments from people may be comforting and sensitive, while others may feel nosey and inappropriate. You may need to plan what you say beforehand to certain people by repeating simple phrases that will discourage unwanted questions. For example: "Our expected baby died and we are very sad but appreciate your concern". Parents find it helpful to alert co-workers prior to their return to work. You can ask your boss or supervisor to inform the office for you. It is important that you respect your personal needs: you do not have to share details if you do not want to.

Family celebrations and other social events where there are children, babies and expecting parents may be difficult for you and your partner to attend. You have every right to decline invitations if you are not ready or feel that it will be too hard for you to handle emotionally.

## Dealing with grief as a couple

You and your partner are dealing with a tragic event. Great sorrow can sometimes bring a couple closer together, but it can sometimes drive people apart. Since everybody grieves differently, you might not always understand your partner's reactions and they can even make you feel angry. You may find that your relationship is forever changed.

It is important to try having open talks; give each other equal time to talk about what you are thinking and feeling. Listen patiently to the other's reaction to the loss. Try to understand without using judgment. You can also reach out to a psychotherapist or attend a support group if you feel things are not going well as a couple.

Keep in mind that grieving takes time and there is no timeline on how to grieve. Each of you can be at a different phase in your grieving process. Gradually your pain will lessen. Surviving a pregnancy or infant loss with your partner can also give you a new appreciation for each other, and for what is important to you as a couple.

If you do not have a partner, you may want to seek support from other sources such as friends, a family member, support groups or a bereaved parent organization.

# If you have other children at home

When children experience the death of a loved one, they also need to grieve - just as adults do. They may not be able to put their grief into words. They may hold their feelings inside or express them through their behavior. They may seem not to be affected, but they are grieving, often very deeply.

As parents, we often want to protect children from the pain of grief. Because we have difficulty dealing with death, we wonder how a child could possibly cope with it, so we keep it from them. However, doing so prevents them from asking us the questions they might have, does not allow them to express their grief and they may struggle to cope with their feelings of loss on their own.

### Ways to help children

- Be direct, simple and honest. Explain truthfully what happened, in words that children can understand.
- Encourage them to express feelings openly. Crying is normal and helpful.

- Accept the emotions and reactions they express. Don't tell them how they should or should not feel.
- Offer warmth and your physical presence and affection.
- Share your feelings with them; allow them to comfort you.
- Be patient. Know that children need to hear "the story" and to ask the same questions again and again.
- Reassure them that death is not contagious—the death of one person does not mean they or other loved ones will soon die.
- Children's magical thinking leads them to believe that they played a role in the person's death. Reassure them that they did not, in any way, cause the death of their baby brother or sister.
- Try to keep their routine the same as much as possible; stability makes them feel safe.
- Allow them to make some decisions about participation in family rituals (for example the funeral, if there is one). Be sure to explain in advance what will happen.

#### Common explanations that may confuse children

Some explanations can make the grief process more difficult or cause problems later in life. Here are some examples of what parents think might be protecting children and what children may actually be thinking:

- The baby went on a long trip "Then why is everyone crying?" "Why didn't we say good-bye?" "I thought vacation trips were supposed to be fun."
- God was lonely and wanted your brother. He was so good that God wants him in heaven "I'm lonely for my brother. I need him more than God does. God is mean!" "If God wants the good people, I'm going to be as bad as I can. I don't want to die."
- Your sister went to sleep "I don't want to go to bed." "I'll make myself stay awake all night so I won't die too."
- We lost the baby "Let's go find her."

#### Some behaviors of grieving children

School work or school life (this applies to daycare too) may be affected by death. Teachers, school counsellors and educators should be made aware of the situation. If serious problems arise on a regular basis, professional help should be sought for the child.

Children may react to death in a variety of ways. Some will have many reactions, some only a few. And some will react immediately while other children may react later. These reactions are very common. They should not be of concern unless they continue for several months or if they increase in intensity or frequency.

# Remembering your baby

Some people may think that the best thing for you to do is forget about your loss and get back to your "normal" life as soon as possible. However, it is hard to simply "get over it". In fact, healing from a loss may take up to 2 years sometimes. Healing involves you remembering the connection you had with your baby even if the baby was not born yet. Recovery can begin when we honor that bond and work through our loss. This is especially important on anniversary dates, such as the expected due date and the day that your baby passed away. It can be helpful for you to find ways to remember your baby, in your own way. Here are some ideas:

- Light a candle in your baby's honor
- Plant a flower, shrub or tree that has a special significance for you
- Make a scrapbook, memory book or memory box
- Plan a funeral if it is important to you
- Place pictures in your house
- Create a space in your house that honors your baby with mementos and/or pictures
- Consider making a donation to a charity that supports perinatal loss in honor of your baby

#### Funeral

The birthing center team will discuss two funeral options with you. You can make arrangements of your own with a funeral home. Many funeral homes offer discounts for a baby's funeral or free cremation.

If you opted for an autopsy, they are usually done within 2 working days of delivery and should not interfere with funeral arrangements. In any case, the funeral home will make the necessary telephone calls and arrangements with the hospital.

If you choose not to plan a funeral, the hospital will arrange for your baby to be cremated, the ashes will be placed in an urn, and the urn will be buried in a community plot with other babies' urns.

## Post partum symptoms

After delivery, you may have vaginal bleeding. This is normal and can persist a few days. If the bleeding increases or the vaginal discharge has a bad odor, <u>come to the Birthing Center</u> triage up to 6 weeks after delivery or go to the <u>Emergency room</u> if more than 6 weeks after delivery. Note that your period may return within 4 to 6 weeks.

You may experience breast engorgement in the first few days after birth. To minimize this, wear a supportive bra and apply cold packs to your breasts.

It is also normal to experience many post-partum symptoms after giving birth, just as you would have if you had delivered a living baby. For more information refer to the *Tiny Tot to Toddler* book or consult the following website:

https://www.inspq.qc.ca/en/tiny-tot/delivery/first-few-days/body-after-birth

## Autopsy information

Preliminary results from the autopsy may be available when you see your doctor 8 to 10 weeks after your delivery. Make sure to ask them to explain them to you. The full autopsy report may only be available 6 to 12 months after your delivery. You can call your doctor if you do not have any news.

# Leave of absence

You may be entitled to maternity benefits. Prior to discharge, ask the doctor for a letter in order to apply for maternity leave.

The hospital social worker can also give you information about leaves.

You can check with the Commission des normes, de l'équité, de la santé et de la sécurité du travail (CNESST) for details about absences and leave you may be entitled to (see <u>Parental leave and preventive</u> withdrawal).

CNESST - 1-844-838-0808

www.cnt.gouv.qc.ca/en/leaves-and-absences/familyevents/maternity-leave/index.html

If your baby died after 19 weeks of pregnancy or right after birth, you are entitled to receive maternity benefits under the Québec Parental Insurance Plan.

Québec Parental Insurance Plan: 1-888-610-7727

https://www.rqap.gouv.qc.ca/en/wage-earners-who-are-also-self-employed/termination-pregnancy

Unfortunately, partners do not have any time off approved by the government after the death of a baby. They must make arrangements with their workplace to determine if they can take a few days off. The doctor can write a medical note for them prior to discharge.

## Suggested resources

#### Support groups:

www.parentsorphelins.org

Parents Orphelins, the Québec Association of parents grieving from pregnancy and infant loss, offers services to parents and relatives (mostly in French)

https://wiwc.ca/support-groups/

The West-Island Women's Centre offers a free support group called Healing together. For more information contact Nadia at outreach@wiwc.ca or by calling 514-781-8529

• <a href="https://starlegacyfoundation.org">https://starlegacyfoundation.org</a>

Worldwide support group: Star Legacy

**Community Resources:** 

Consult your local CLSC to find out about services in your area.

To find the CLSC in your area, visit

www.sante.gouv.qc.ca/en/repertoire-ressources/clsc

Free photo services and photo editing

Fondation Portraits d'Étincelles - 1-877-346-9940

Free photo and photo touch-up service for babies who died prior to or at birth.

www.portraitsdetincelles.com

#### Videos

Revenir les bras vides - CHU Sainte-Justine (Most sections in French)
A series of free videos and information documents on perinatal grief.
www.chusj.org/fr/soins-services/C/complications-degrossesse/Deuil-perinatal-mort-perinatale

Quand passe la tempête, Le deuil des pères

A video on fathers' grief.

UQO – L'université de l'Outaouais et des Laurentides http://www.youtube.com/watch?v=kW\_cQMqflhM

#### Suggested readings about siblings

 How Do We Tell the Children? A Step-by-Step Guide for Helping Children Two to Ten Cope When Someone Dies by Dan Schaefer and Christine Lyons

#### Suggested readings for siblings

- Baby Bear Has Died by Ginette Mantha (Préma-Québec)
- Sad Isn't Bad: A Good-Grief Guidebook for Kids Dealing with Loss by Michaelene Mundy
- Does everyone die by Lynne Pion
- The Dragonfly Door by John Adams & Barbara L. Gibson
- Something Happened: A Book for Children and Parents Who Have Experienced Pregnancy Loss by Cathy Blanford
- The Fall of Freddie Leaf by Leo Buscaglia

#### Popular books to read

- Empty Cradle, Broken Heart: Surviving the Death of Your Baby (Revised Edition) by Deborah L. Davis, Ph.D. \*\*
- Les rêves envolés by Sylvie Fréchette-Piperni

### Fill-in yourself book about your pregnancy

I love you still by Margaret Scofield

A memorial book to hold memories for babies taken too soon.

#### Other useful websites

- Prema Quebec
   http://www.premaguebec.ca/fr/services/soutien-cas-de-deuil/
- <u>www.nospetitsangesauparadis.com</u> (in French)
- Tommy's Foundation https://www.tommys.org
- Center for Loss in Multiple Births (CLIMB)
   For twin/triplet pregnancies with a loss: <u>climb-support.org/</u>
- Stars of remembrance

A memorial space for babies lost in pregnancy, where you can name a star after your baby and leave a personalized message.

https://www.miscarriageassociation.org.uk/your-feelings/marking-your-loss/stars-of-remembrance/

This pamphlet has been printed thanks to the financial support of the McGill University Health Centre Foundation. For more information or to make a donation please visit the website:

https://muhcfoundation.com/