Losing your baby A short guide about perinatal loss





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The information provided by this booklet is for educational purposes. It is not intended to replace the advice or instruction of a professional healthcare practitioner or to substitute for medical care. Contact a qualified healthcare practitioner if you have any questions concerning your care.

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 birth, is something that we never imagine happening, which makes this type of loss very painful. Perinatal loss is also often misunderstood by those who have not lived through it, which can make the grieving process more difficult.

This booklet will help you:

- find resources and information to support you as you grieve,
- understand and work through the emotions you and those around you may feel,
- navigate through this difficult time, knowing that you are not alone.

What makes this type of loss different?

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

Disenfranchised grief is when you mourn the death of your baby, but feel that you cannot talk or share your feelings about it because it is not socially accepted to do so. Many people will not understand that even if your baby was not born yet, you were already attached to your child and had included them in your life plans. In the case of a stillbirth, some people may have trouble understanding that babies can die before delivery.

You may also have a hard time talking about your grief with others because they might not be comfortable with the topic of perinatal loss. This can make the grieving process more difficult and painful. You may not receive the same care and attention you would have if a loved one had passed away in your family.

What can I do?

Although no one will be able to say or do anything to 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 parents who have lived through the same type of loss. You need 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 and get by: you are in survival mode. Take the time to care for yourself. Here are a few suggestions:

• Treat yourself with comfort and care

You have just been through a traumatic experience, physically and mentally. 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 people 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 as any death would affect someone.

• Let your body lead you

We all react differently to grief. Some people may not be able to move or think, while others may keep busy and stay active. Listen to what your body tells 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 coworkers

Pregnancy loss can be an awkward subject for many people. Explaining your loss to others can leave you feeling drained or 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 comments. 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 or inappropriate. You can plan simple phrases ahead of time that will discourage unwanted questions. Here is an example: "Our expected baby died and we are very sad, but appreciate your concern."

You may also find it helpful to alert co-workers before returning to work. You can ask your boss to inform the office for 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 or expecting parents may be difficult for you and your partner. You have every right to decline invitations if you are not ready or feel that it will be too hard for you to handle.

Dealing with grief as a couple

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

Try to have open talks: give each other equal time to talk about your thoughts and feelings. Listen patiently to their reaction to the loss. Try to understand without judgment. You can also reach out to a psychotherapist or attend a support group as a couple if you feel things are not going well. Keep in mind that grieving takes time. Each person grieves at their own pace. Each of you can be at a different phase in your grieving process. Slowly, your pain will lessen. Surviving a pregnancy loss or infant loss with your partner can also give you 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 friends, family members, support groups or a bereaved parent organization.

If you have other children at home

When children experience the death of a loved one, they 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 behaviour. 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 trouble dealing with death, we wonder how a child can possibly cope with it, so we keep it from them. But doing this prevents children from asking us questions they might have. It also does not allow them to express their grief and may leave them to struggle with their feelings of loss on their own.

Ways to help children

- Be direct, honest and keep it simple. Explain what happened in words that children can understand.
- Encourage them to express feelings openly. Crying is normal and helpful.
- Be warm, physically present and show affection.
- Accept the emotions and reactions they express. Don't tell them how they should or should not feel.
- Share your feelings with them; allow them to comfort you.
- Be patient. 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 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 helps them feel safe.
- Allow them to make some decisions about taking part in family rituals (for example, the funeral, if there is one). Be sure to explain what will happen ahead of time.

Common explanations that may confuse children

Some explanations can make the grief process harder or cause problems later in life. Here are some examples of what parents might say to protect 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 goodbye?" "I thought vacations 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 too. I need my brother 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 behaviours of grieving children

Your child's behaviour at school or daycare may change. Take the time to alert teachers, school counsellors or educators so that they better understand what your child may be going through. If serious problems come up on a regular basis, you should consider professional help for your child.

Children may react to death in many ways. Some will have many reactions, others only a few. Some will react immediately, while others may react later. These different responses are normal. They should not worry you unless they continue for many months, get more intense or happen more often.

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." Healing from a loss can sometimes take up to 2 years. It involves remembering the connection you had with your baby, even if the baby was not born yet.

Recovery can begin when we honour 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 honour.
- Plant a flower, shrub or tree that has a special meaning for you.
- Make a scrapbook, memory book or memory box.
- Plan a funeral.
- Create a space in your house with mementos or pictures to remember your baby.
- Place pictures in your house.
- Donate to a charity that supports perinatal loss in honour of your baby.

Funeral

The birthing centre team will discuss your options with you. If you choose to have a funeral, you will need to 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 business days after the delivery and should not impact funeral arrangements. In any case, the funeral home will make any needed telephone calls and arrangements with the hospital.

If you choose not to have a funeral, the hospital will arrange for your baby to be buried or cremated. Your baby will be buried in a community plot with other babies.

Autopsy information

Initial 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 the results 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.

Postpartum symptoms

After delivery, you may have vaginal bleeding. This is normal and can last for a few days.

If the bleeding increases or the vaginal discharge has a bad smell:

- Up to 6 weeks after delivery: Come to the Glen Site's Birthing Centre triage area.
- More than 6 weeks after delivery: Go to an Emergency department.

Note that your period may return within 4 to 6 weeks.

You may have breast engorgement (swelling) in the first few days after birth. To help with this, wear a supportive bra and apply cold packs to your breasts.

It is also normal to feel many postpartum 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 site: <u>inspq.qc.ca/en/tiny-tot/delivery/first-few-days/body-</u> <u>after-birth</u>

Leave of absence

You may be entitled to maternity benefits. You will receive a letter from the doctor that you can use to apply for maternity leave. The hospital social worker can also give you information about taking a leave.

Check with the **Commission des normes, de l'équité, de la santé et de la sécurité du travail (CNESST)** for details about leaves you may be able to take:

- 1-844-838-0808
- <u>cnesst.gouv.qc.ca/en/working-conditions/leave/family-related-</u> <u>leave/adoption-or-birth/maternity-leave</u>

• See also INSPQ's page: <u>inspq.qc.ca/en/tiny-tot/useful-</u> <u>information/becoming-parent-government-programs-and-</u> <u>services/parental-leave-and-preventive-withdrawal</u>

If your baby died after 19 weeks of pregnancy or right after birth, you can receive maternity benefits under the **Québec Parental Insurance Plan:**

- 1-888-610-7727
- rqap.gouv.qc.ca/en/wage-earners-who-are-also-selfemployed/termination-pregnancy

Partners are entitled to 5 days off if your baby was born at 20 weeks of pregnancy or after. The leave must be taken within 15 days following the birth. The doctor can write a medical note for them before you leave the hospital.

• <u>cnesst.gouv.qc.ca/en/working-conditions/leave/family-related-</u> <u>leave/adoption-or-birth/five-day-leave</u>

Suggested resources

Support groups

<u> Le Phare – Enfants et Familles</u>

Pediatric palliative care home in Montreal offering free and unlimited grief support to parents, siblings and grandparents in the context of perinatal loss. Write to <u>psychosocial@phare-lighthouse.com</u> or call 514-787-8818. <u>https://phare-lighthouse.com/en/</u>

West Island Women's Centre

Offers a free support group called *Healing Together*. For more information, write to <u>outreach@wiwc.ca</u> or call 514-781-8529. <u>wiwc.ca/support-groups</u>

Family care collective

Peer support group with experienced facilitators. Write to info@familycarecollective.org for information and to register. familycarecollective.org/support-groups

Indigenous Health Centre of Tiohtià:ke

Health navigator, traditional healer and psychotherapy for Indigenous patients. Write to <u>info@ihct.ca</u> or call 514-482-8557. <u>https://ihct.ca/</u>

Community resources

Consult your local CLSC to find out about services in your area. To find the CLSC in your area, visit:

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

Free photo services and photo editing

Fondation Portraits d'Étincelles Free photo and photo touch-up service for babies who died before or at birth. Site in French only. Call 1-877-346-9940 portraitsdetincelles.com

Videos

<u>Revenir les bras vides – CHU Sainte-Justine</u> A series of free videos and information on perinatal grief (in French). <u>chusj.org/fr/soins-services/C/complications-de-grossesse/Deuil-</u> <u>perinatal-mort-perinatale</u>

Quand passe la tempête, le deuil des pères – L'Université du Québec en Outaouais (Gatineau et St-Jérôme)

A video about fathers and perinatal grief (in French). youtube.com/watch?v=kW_cQMqflhM

Suggested readings

<u>About siblings</u>

• 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

<u>For siblings</u>

- Baby Bear Has Died by Ginette Mantha (Préma-Québec)
- Something Happened: A Book for Children and Parents Who Have Experienced Pregnancy Loss by Cathy Blanford
- Does Everyone Die? by Lynne Pion
- The Dragonfly Door by John Adams & Barbara L. Gibson
- The Fall of Freddie Leaf by Leo Buscaglia

<u>Popular books</u>

- 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 book about your pregnancy

- I love you still by Margaret Scofield
- A memorial book to hold memories for babies taken too soon.

MUHC McConnell Patient Resource Centre

For more information about perinatal loss and grief, visit the McConnell Patient Resource Centre's online resource pages:

- Perinatal loss: muhclibraries.ca/perinatal-loss
- Grief: muhclibraries.ca/grief
- Main website: <u>muhclibraries.ca/patients</u>

For help finding reliable health and wellness information, email <u>crp-</u><u>prc@muhc.mcgill.ca</u>.

Other useful websites

Parents Orphelins parentsorphelins.org

<u>Tommy's Foundation</u> tommys.org

<u>Center for Loss in Multiple Births (CLIMB)</u> 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. <u>miscarriageassociation.org.uk/your-feelings/marking-your-</u> <u>loss/stars-of-remembrance</u>