



## Perinatal loss: Losing a baby



Now that you are gone,  
my *heart* is broken.  
But because  
*you were once here,*  
it is COMPLETELY filled with  
**love.**

## INTRODUCTION

You have suffered a terrible loss.

Losing a baby, whether during pregnancy or just after birth is considered “out of the normal order” of life, which makes this type of loss particularly painful. As well, a perinatal loss is often misunderstood by society, which can make the grieving process even more difficult.

We hope this booklet will help you understand what can make a perinatal loss different, how you can help yourself through this process, and how others can support you.

## WHAT MAKES THIS TYPE OF LOSS DIFFERENT?

We all know death is a part of life, but most of us don't expect to lose a child, especially before he or she is born, or shortly after birth.

Whether your baby died because of a miscarriage, or because you made the hard decision of ending the pregnancy for any reason, or your baby died once born, you may be experiencing what is called “disenfranchised grief.” “Disenfranchised grief” means that you are mourning the death of your baby, but that you may feel you can't talk about it or share your pain with others because it is considered unacceptable to others.

Most people do not understand that even if your baby wasn't born yet—as in the case of a miscarriage or a pregnancy termination—you were already feeling attached to your child. In the case of stillbirth, people may find it hard to deal with the fact that babies can die at birth.

Whatever the case, because of society's discomfort with this topic, you can feel that it's best not to talk about your grief because it makes others feel uncomfortable, which can make it even more intense. This is what disenfranchised grief is: unlike the funerals we attend, and the comfort and visits we offer other mourners when they have lost a loved one, those who have suffered a perinatal loss often do not receive the same type of care and attention.

## SO WHAT CAN BE DONE?

Though nothing someone does or says can fix this, it is important that you talk about how you're feeling with someone you trust and who cares about you. This may be a family member, a friend, a professional who knows about perinatal loss; or it can be joining a support group with other parents who have experienced the same type of loss. What is key is that you have the

chance to work through your grief. We have collected some ideas in this booklet that we hope will help you.

### THE FIRST FEW DAYS & WEEKS

It is important in the first few days and weeks after a perinatal loss that you take care of yourself. Right now, you are simply coping, getting by, surviving. Here are a few suggestions:

- **Treat yourself as if you are in need of comfort and care**—you have been through a very traumatic experience, both on a physical and psychological level. Therefore, even though you might want or think it is best to get back to your “normal life,” you should focus on your basic needs, such as resting and eating well.
- **Someone to take calls or contacting people**—understandably people may want to reach out to you to see how you’re doing. It’s okay if you don’t want to take calls or answer texts or e-mails; find a family member or friend who would be willing to do that for you for the time being. And remember, it’s okay to say your baby died; that way you are telling people that this can happen and that it is affecting you.
- **Let your body lead you**—we all react differently to grief; some of us may feel we can’t move or think, while others may feel very busy and active. Make sure you listen to what your body is telling you: if you need to sleep, sleep; if you want to cry, cry. Remember, there are no rules and “should” when it comes to grief.
- **Have someone near you**—if possible, have your partner or a close friend or other family member close by. Let that person help you make decisions, hear your fears and concerns and be the shoulder you can lean on.

### COPING WITH FRIENDS, FAMILY & CO-WORKERS

Pregnancy loss remains an awkward subject for many. Explaining your loss to family, friends and co-workers can leave you feeling drained and angry, especially if people’s remarks are thoughtless and unkind. Once you are ready to talk about your loss, you need willing listeners who make you feel loved and valued.

Sometimes other people may not realize how upset you are—they either avoid the topic or make a clumsy remark. Others may truly help—offering to bring a meal or make necessary phone calls. You should feel free to ask for help.

Some comments from other people may be comforting and sensitive, others may feel nosy and inappropriate. Plan what to say beforehand; find several simple but comfortable phrases that discourage unwanted questions, for example, *“Our expected baby died and we are very sad. But we appreciate your concern.”* Mothers find it helpful to alert co-workers before returning to work, for example by asking a supervisor to inform the rest of the office. Importantly, respect your personal needs: you don’t need to share details if you don’t want to.

Participating in family celebrations and other social events where there are children and babies may be difficult for you and your partner. You have the right to decline invitations if you feel it will be too much for you to handle emotionally.

### DEALING WITH GRIEF IN YOUR COUPLE

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

Try to have open talks; give each other equal time to talk about what each of you is thinking and feeling. Listen patiently to each other’s reaction to your loss. Try to understand without judging each other. Remember, a support group or psychotherapist might be helpful if you’re feeling that things are not going well. Keep in mind that it takes time to grieve. Each of you may be at a different place in your grief. Gradually your pain will lessen. Surviving a pregnancy or infant loss with your partner can 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, support groups and bereaved parent organizations.

### 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. This means that we might be leaving them to answer their questions on their own as they struggle to cope with their loss, and they may not know how to deal with their grief.

### Ways to help children

- Be direct, simple and honest. Explain truthfully what happened in terms 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—that 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 on one hand 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 (as if the case for 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(ren).

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 think the best thing you can do is forget about your loss, and get back to your life as soon as possible. But “getting over it” is sometimes difficult. In fact, healing from grief involves remembering the connection you had with your baby, even if he wasn’t born yet. It is only when we honor that bond, and work through it that we can recover. This is especially important on anniversary dates, such as the expected due date or the date your baby died. So, it’s important that you find a way to remember your baby in your way. Here are some ideas:

- light a candle in your baby’s honor
- release a balloon with a note attached (check with your municipality first to make sure you’re not violating any by-laws)
- plant a flower, shrub or tree that has special significance for you
- make a scrapbook or memory box of mementos (cards, photos, receiving blanket, etc.)

***Consider making a donation to a charity that supports a cause that is important to you: for example the McGill University Health Centre Foundation organizes a fundraising campaign for perinatal loss. For more information consult the site:***

***<https://muhcf.akaraisin.com/cradles>***

## SUGGESTED RESOURCES

### SUPPORT GROUPS

- MUHC Perinatal loss support group
  - [info@ndgtherapy.com](mailto:info@ndgtherapy.com) for information and to register
- [www.parentsorphanins.org](http://www.parentsorphanins.org)

Parents Orphanins, the Québec Association of parents grieving from pregnancy and infant loss, offers services to parents, relatives and health care professionals going through this difficult ordeal. Their goal is to break the isolation, document, inform and educate the population of Québec on the subject of pregnancy and infant grief.

### READINGS

Suggested readings for parents (\*\* Available at MUHC McConnell Resource centre B.RC.0078)

- *Empty Cradle, Broken Heart: Surviving the Death of Your Baby (Revised Edition)* by Deborah L. Davis, Ph.D. \*\*
- *Words from the heart: a book on perinatal loss* by Sarah Bachand & Caroline Labrie
- *The prenatal bombshell : help and hope when continuing or ending a precious pregnancy after an abnormal diagnosis* by Stephanie Azri & Sherokee Ilse \*\*
- *Tears of Sorrow, Seeds of Hope* by Rabbi Nina Beth Cardin 2007
- *I Never Held You: A Book about Miscarriage, Healing and Recovery* by Ellen M. DuBois 2006
- *Ghostbelly: A Memoir* by Elizabeth Heineman
- *Bearing the unbearable: Love, loss and the heartbreaking path of grief* by Joanne Cacciatore \*\*
- *Joy at the end of the rainbow: A guide to pregnancy after a loss* by Amanda Ross-White\*\*
- *Coping with infertility, miscarriage, and neonatal loss : finding perspective and creating meaning* by Amy Wenzel \*\*
- *An Empty Cradle, A Full Heart: Reflection for Mothers and Fathers After Miscarriage, Stillbirth or Infant Death* by Christine O'Keeffe Lafser
- *A Guide for Fathers: When a Baby Dies* by Tim Nelson 2004
- *How to Survive the Loss of a Child: Filling the Emptiness and Rebuilding Your Life* by Catherine Sanders, Ph.D.
- *When Hello Means Goodbye* by Pat Schwiebert & Paul Kirk
- *Grieving the Child I Never Knew* by Kathe Wunnenberg

Suggested readings for grandparents

- *Healing your grieving heart after stillbirth: 100 practical ideas for parents and families* by Alan D Wolfelt & Raelynn Maloney \*\*

- *Healing your grieving heart after miscarriage: 100 practical ideas for parents and families* by Alan D Wolfelt & Raelynn Maloney \*\*
- *Forgotten Tears: A Grandmother's Journey Through Grief* by Nina Bennett 2005

#### Suggested readings about siblings

- *Talking About Death: A Dialogue Between Parent and Child* by Rabbi Earl Grollman
- *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
- *Lifetimes: The Beautiful Way to Explain Death to Children* by Bryan Mellonie
- *I Miss You: A First Look at Death* by Pat Thomas
- *Gentle Willow: A Story for Children About Dying* by Joyce C. Mills

### ONLINE RESOURCES

#### **General support for infant loss**

- <http://tcfcanada.net/>

The Compassionate Friends Canada offers support via a helpline, local chapter meetings, one-to-one visiting and library resources. The support group is led by bereaved parents.

- [www.nospetitsangesauparadis.com](http://www.nospetitsangesauparadis.com) (in French)

Nos petits anges aux paradis: groupe de soutien virtuel pour parents vivant un deuil périnatal.

- <http://www.premaquebec.ca.fr/services/soutien-cas-de-deuil/>

Préma-Québec offers telephone support, documentation on grief and a closed support group on Facebook : Préma-Québec - Parents endeuillés.

- <http://www.climb-support.org/>

The Centre for Loss In Multiple Birth is a non-profit organization which provides parent-to-parent support for parents who have experienced the death of one or more twins or higher multiple birth children at any time from conception through birth, infancy and early childhood. It is also to assist extended families, caregivers, twins and multiples organizations and others who are seeking to understand and support the needs of parents with a multiple birth loss.



## MUHC McConnell Resource centre (Glen site B.RC.0078)

- <http://www.muhclibraries.ca/patients/health-topics/perinatal-loss/>

## Education and support for women and men facing infertility issues

- [www.infertilitynetwork.org](http://www.infertilitynetwork.org) (Canadian)

The Infertility Network (IN) strives to: provide support and information to help people make informed choices about their family-building options; develop public understanding and awareness of infertility, reproductive technology and related issues

## OTHER ONLINE RESOURCES

- [www.nationalshare.org](http://www.nationalshare.org)

SHARE is a resource center for parents who have lost a baby before, at or shortly after birth. Its website has articles, information, and a chat room

- [www.hopeafterloss.org](http://www.hopeafterloss.org)

The Hygeia Foundation is a non-profit organization. It provides programs to educate, counsel and support families who grieve the loss of a pregnancy or newborn child, advocate for the healthcare of women and children worldwide, and promote humanism in the education of tomorrow's healthcare professionals.

- [www.griefwatch.com](http://www.griefwatch.com)

Grief Watch provides bereavement resources, memorial products and links that can help you through your personal loss. Products are available that are specific to pregnancy loss, such as *Strong and Tender* (a book for fathers) and various personalized cards and announcements.

- [www.aplacetoremember.com](http://www.aplacetoremember.com)

*A Place to Remember* offers resources for infant loss, including books, announcements, memory boxes, and materials for bereaved families

- [www.babysteps.com](http://www.babysteps.com)

General support for the loss of a child

- [www.griefnet.org](http://www.griefnet.org)

E-mail support groups for bereaved parents, siblings, and grandparents. Also comprehensive resource lists and a sister website for bereaved children, KIDSAID at [www.kidsaid.com](http://www.kidsaid.com)

- [www.resolve.org](http://www.resolve.org)

Education, advocacy and support for women and men facing infertility. Includes a help line and monthly magazine.

## SONGS

- « *Les petits pieds de Léa* » de Céline Dion
- « Glory Baby » (Watermark)

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**<https://muhcf.akaraisin.com/cradles>**