

# LOSING A CHILD

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A guide for parents



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## Acknowledgements

We would like to thank Michèle Viau-Chagnon (Palliative Care Program, Montreal Children's Hospital) for her book entitled *Pour ce deuil qui vous afflige... repères pour parents endeuillés*, which greatly inspired the creation of this guide.

# Introduction

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*"There is nothing more difficult for a parent than losing a child. No matter your child's age or the cause of their death, it feels unfair, even unreal. The shock is so overwhelming, and the pain so profound, that you're left not knowing how to react..."*

Michèle Viau-Chagnon  
Critical and palliative care consultant at  
Montreal Children's Hospital

This guide complements the information you have received in person from the healthcare team.

You will find information on the grieving process, funeral rites, your own potential reactions, and those of your other children and loved ones.

There is also a list of helpful resources such as books and support groups for you and your loved ones, as well as some parent testimonials.

Go at your own pace, according to your needs.

## By your side

We are here to support you in the days ahead, to help you through this difficult time. We will take into account your wishes, your needs, your beliefs and rituals, as well as our practical considerations.

# What are the stages?

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## From the care unit to the funeral service

In the following paragraphs, we will outline the care provided to your loved one in our facility, the journey to the funeral home, and guidance on administrative procedures.

Siblings and other loved ones are welcome at any time.

Washing the body forms part of the care we provide. You may wish to do this yourself or with the support of a healthcare worker. You may also wish to keep a lock of hair, make hand or foot prints, or have photographs taken. Please don't hesitate to ask us.

The healthcare worker will escort you to the cool room. This is a place where you and your loved ones can be with your child at any time of the day or night during the first 24 hours. The body is then transferred with your agreement to the University Medical Centre (UMC).

The UMC will take care of your child's body until the funeral home that you have instructed takes over. You will not be able to be with your child during this time. Please make sure that you hand over any clothing and personal items that are to accompany your child directly to your funeral director, as the UMC cannot guarantee their delivery.

The funeral home will care for your child's body with dignity and compassion. The funeral director is there to provide information and guide you through every step – from organising the funeral and co-ordinating service providers to helping with administrative formalities or repatriation arrangements.

You need to get a death certificate issued by the register office in the place of death; a family record book is required or alternatively a birth certificate. The death must be registered within two days. There is no legal maximum time limit for burial or cremation. You can undertake these arrangements yourself or through the funeral director.

# Support resources

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## Chaplaincy

Spiritual support is provided by the chaplaincy team at HUG.

For people of different faiths, religions or none, the chaplaincy team can put you in touch with the various communities established in Geneva. Spiritual support is also available to those without religious affiliation.

The chaplaincy team is available 24/7, offering support to hospital patients and those grieving the loss of a child.

The team offers spiritual or religious support that fully respects your personal needs and beliefs, while maintaining the strictest confidentiality within an interfaith setting.

 022 372 85 90

## Rites

If you wish to spend time with your child – whether through blessings and prayers, sharing a meaningful text, or performing a personal gesture that holds special significance for you – our chaplaincy team is on hand to help create this important moment together.

## Child and adolescent psychiatry service

At our Child and Adolescent Centre, psychologists and child psychiatrists provide support to families and siblings both during and after hospitalisation to help them navigate through difficult events.

This support works alongside the healthcare teams, allowing families to feel supported, heard, and able to express their suffering in words.

Some families make initial contact with us shortly after the loss and then receive ongoing support in the period that follows the initial shock.

 022 372 48 00

## Healthcare teams

The healthcare teams are always available to answer any future questions you may have.

## PASSO

The paediatric support team for supportive and comfort care (PASSO) offers families comfort and support to help them navigate their child's complex medical journey. The team offers healthcare support to bereaved families during this difficult time, whether or not the child was previously under the team's care. In collaboration with PASSO, the chaplaincy team also offers personalised support to families of children in paediatric oncology care.

The PASSO team will listen to you with compassion and help you find the best support for your family across French-speaking Switzerland. They can also help you get back in touch with your child's care team if you wish.

 079 553 04 31

 [passo@hug.ch](mailto:passo@hug.ch)

## Social work service

The social work department at the Children's Hospital is also available to support you at the time of your child's death. It can provide help with social and administrative matters. The social worker reviews each case individually.

 079 553 31 91

# What is bereavement?

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The length of the grieving process varies greatly from person to person (father, mother, brother or sister).

There is no single way to grieve, and sometimes families feel that they will never get through this ordeal.

One of the aims of 'grief work' is to express feelings about the loss of a child, brother or sister, to eventually learn to live without them, while continuing to keep them in your thoughts and integrating them into family life.

## Grieving

The onset of a sudden illness or the loss of a loved one triggers a psychological process known as the grieving process.

Grieving is the experience of the psychological, social and physical reactions related to the loss of a loved one. It is a normal psychological process experienced by all those who lose someone close to them.

Each person (parents, brothers and sisters) experiences the different stages of grief at their own pace, shaped by personal history and an individual understanding of death.



## **The initial shock**

Disbelief and denial. The reality is so overwhelming and unthinkable that people experience phases of complete disbelief alternating with moments of self-protection when they shield themselves from the painful truth of their loss. The mind protects itself from reality: one part of a person grasps the loss, while the other hopes for change or denies it altogether.

## **Anger and protestation**

This more active phase enables families to emerge from their feeling of powerlessness and to seek the cause of their loved one's loss. Anger may turn inward, with families taking on the burden of responsibility for what has happened. Sometimes the anger is directed at other people (such as those close to them or the health-care team). Feelings of aggression or isolation may then arise.

## **Sadness**

As the families become aware of the permanent nature of the situation, the loss becomes a reality. Feelings such as anxiety, fear and the pain of loss emerge. This sadness is a natural part of the grieving process.

## **Acceptance**

The family tries to make sense of the events and to adapt to their loss. Parents begin to remember the child they have lost through shared, happy memories. They continue living, integrating their child into their thoughts, without being overwhelmed and consumed by grief.

## **Bereavement in children and siblings**

Children's understanding of death is different depending on their age. Here's an overview of the stages:

### **Under 2 years**

There is a complete lack of understanding of death; death is more closely associated with the absence of the person, with separation.

### **From 2 to 4–6 years**

Death is not recognised as final; it is seen as temporary or reversible.

### **From 4–6 to 9 years**

Death is personified, for example as a corpse, skeleton or cemetery. The person dies, but at the same time, they are still somehow present – they simply cannot move or breathe.

There is a gradual shift in understanding from the death of a single person to a universal truth: all people die, starting with the elderly.

### **From 9–11 years to adolescence**

Children start to grasp the moral and universal significance of death, alongside the very real experience of losing loved ones, which triggers feelings of existential anxiety.

## Approach to siblings

Some advice on supporting siblings.

### Supporting your children

It is important for your children that you share the news about the death of their brother or sister. We can provide support if you wish.

Don't keep the news from them for too long.

Share the facts in a way they can understand, and be ready to answer their questions.

**If your children want to**, give them the opportunity to say goodbye to their brother or sister. Encourage siblings to be part of the grieving process by including them in the various family events (blessing, reflection, funeral service).

**Don't be afraid** to share your feelings and express your sadness using age-appropriate language. However, your children may have very different reactions depending on their personality, age, history and the relationship they had with their brother or sister.

## Parent testimonials

### **Here are the words of mothers who have lost a child:**

"I was someone who liked to feel in control of my life. I wanted two children; my life was all mapped out. Losing a child turned my world upside down. I realised that plans can suddenly fall apart. My daughter's death showed me how fragile life is and took away my deep sense of security. This feeling has faded, but I have never regained that same sense of peace. Life is fragile, but now I cherish the people I love even more. I'm also better equipped to deal with difficult situations."

"After our child died, I thought I'd never have any kind of routine again. But now I've got back into some of my routines. I've regained a sense of security; part of me is healing. I've managed to reorganise my life, and my interests have changed a little. Another part of me will always remember, every day, every month. With time, it will become less painful."

# Bibliography

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The titles presented here are in French; English versions may also exist.

## Books for parents

*Lorsque la vie éclate, l'impact de la mort sur la famille*,  
L. Beaudet, F. de Montigny, Éd. Seli Arslan, Paris, 1997.

*Les enfants en deuil. Portraits du chagrin*,  
M. Hanus, B.M. Sourkes, Éd. Frison-Roche, Paris, 1997.

*La mort et l'enfant*, E. Kübler-Ross, Ed. du Tricorne, Genève, 1986.

*Parler de Dieu avec les enfants*, J. Chabert, F. Mourvillier,  
Éd. Centurion, Paris, 1990.

*Dis, pourquoi la mort ?*, M. Leist, Ed. Cana, Paris, 1981.

*Les enfants et Dieu*, R. Coles, Éd. Laffont, Paris, 1993.

*Aimer, perdre et grandir*, J. Monbourquette,  
Éd. du Richelieu, Paris, 1984.

*Le deuil périnatal: le vivre et l'accompagner*,  
C. Haussaire-Niquet, Éd. Le Souffle d'or, Paris, 2004.

## Books for children

### From 3 years

*Si on parlait de la mort*, C. Dolto, F. Mansot (illustrations),  
Éd. Gallimard jeunesse-Giboulées, Paris, 2005.

Cet ouvrage permet de découvrir la notion de cycle de vie et rassemble toutes les interrogations des enfants face à la mort.

### From 4 years

*Petit lapin Hoplà*, Elzbieta, Éd. L'École des loisirs, Paris, 2001.

Sous la forme d'une comptine, ce petit livre, plein de tendresse et de délicatesse, aborde les thèmes de la mort et du deuil.

### From 5 years

*Le petit livre de la mort et de la vie*, D. Saulière, R. Saillard (illustrations),  
Éd. Bayard Jeunesse, Coll. Petits guides pour comprendre la vie,  
Paris, 2005.

*L'étoile de Léa*, P. Gilson, C. K. Dubois (illustrations),  
Éd. Mijade, Namur, 2002.

Tous les jours, Baptiste et Léa parcourent ensemble le chemin de l'école. Aujourd'hui, plus. Gravement malade, Léa est entrée à l'hôpital. Les enfants de sa classe ont décidé de lui rendre visite et ils découvrent alors sa maladie et l'univers médical. Baptiste viendra tous les jours voir Léa et il l'accompagnera jusqu'au seuil de la mort. Cet album a été réalisé par un enseignant et ses élèves, avec la collaboration d'organismes de soins palliatifs. Très réaliste, il évoque le manque, la culpabilité, la tristesse, la maladie, la complicité... avec une certaine pudeur et met en évidence les questions que se posent les enfants face à la maladie.

*Quelqu'un que tu aimes vient de mourir*, I. Hanus, N. Dufour,  
Éd. Vivre son deuil. Cahier de dessin et d'écriture.

### **From 7 years**

*Quelqu'un que tu aimais est mort*, A. Auschitzka, N. Novi (illustrations),  
Éd. Bayard/Centurion, Paris, 1997.

Livre-compagnon pour aider à retrouver goût à la vie, confiance en soi, en Dieu.

*Leïla*, S. Alexander, G. Lemoine (illustrations), Éd. Bayard, Paris, 1986.  
Conte bédouin, Leïla ne veut pas oublier son frère disparu dans le désert.

### **From 8 years**

*Véra veut la vérité*, L. et N. Huston, W. Glasauer (illustrations),  
Éd. L'école des loisirs, Coll. Mouche de poche, Paris, 1994.  
Histoire pour les enfants qui s'interrogent sur la mort.

### **From 10 years**

*La vie et la mort*, B. Labbé, M. Puech, J. Azam (illustrations),  
Éd. Milan, Coll. Les goûters philo, Paris, 2005.  
Philosophie de la mort et de la vie, humoristique.

*Aimer, perdre et grandir*, J. Monbourquette,  
Éd. du Richelieu, Paris, 1984.

# Contacts

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## Bereavement support groups

Arc-en-ciel (support for parents who have lost a child)

Vanessa Binder

 078 751 74 54


Caritas

Marthe Hofstetter

Laurianne Neidecker

 022 784 01 69

 022 784 42 58

 078 899 35 11

Isabelle Nielsen

Support sector

 022 708 04 44

As'trame Genève

Support for children and adolescents

 022 340 17 37

Résiliam (bereavement support for children)

 <http://resiliam.ch>

 022 342 31 59

## Websites

 <https://lenfantsansnom.fr>

Bibliography, discography, testimonials

 [www.association-kaly.org](http://www.association-kaly.org)

 079 532 29 44

# Useful contacts

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## Department for Women, Children and Adolescents

Switchboard  022 372 40 00

Outpatient appointments -  
Early Childhood Guidance  022 372 89 89

*"A life completed is a life accomplished. Just as a single drop of water reflects the vastness of the ocean. Tiny lives, with their brief beginnings, their infinitesimal zenith, their swift ending, have no less meaning than the longest journeys. Lean in a little to see them, to magnify them and tell their stories."*

Françoise Chandernagor

Cited in French in *Le deuil périnatal: le vivre et l'accompagner*,  
by Chantal Haussaire-Niquet.